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Young Deaf Adults' Knowledge of Human Papillomavirus (HPV) and Perceived Risk of Vaccine in Preventing Cervical, Anal, Penile, and Oral Cancer

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Abstract

Study Objective: Describe knowledge and risk perception of Human Papillomavirus (HPV) among deaf adults who use American Sign Language (ASL) in comparison to 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 based on catchup vaccine eligibility criteria as outlined by the CDC 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.

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PK designed the research, gathered data, analyzed the data, and wrote the paper; AS and CM provided intellectual content and wrote the paper; PK had primary responsibility for the final content. All authors read and approved the final manuscript.

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Results: Our sample consisted of 235 deaf and 115 hearing adults aged 18-26. Of the deaf participants 58% reported knowledge of HPV compared to 84% of hearing participants ($p<0.001$). Hearing participants demonstrated higher accuracy in risk perception of HPV relation to cervical cancer as compared to deaf participants ($p< 0.001$). Hearing participants were more likely to have heard of the HPV vaccine as well as believe it is successful in preventing cervical cancer as compared to deaf participants. ($p< 0.001$).

Conclusion: Deaf ASL users are less likely to have knowledge of HPV, virus related cancer risk, and preventative vaccination as compared to hearing peers.

Keywords

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 to 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 with catchup vaccination routinely recommended for all males through age 21, and males in high risk categories such as those who are immunocompromised or identify as having sex with men, women, and transgender adults through age 26.[8] Males aged 22 to 26 wishing protection and not previously immunized may receive the vaccination. Despite these recommendations, endorsed by the Centers for Disease Control and Prevention (CDC) and other professional medical organizations, national completed vaccination rates estimated in 2017 were found to be only 66% for adolescents.[9] Although addressing parental perception and knowledge of HPV is critical in the effort to improve vaccination rates, as vaccines are recommended to be given during childhood, not all young adults have been vaccinated themselves and may 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 US, 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 cancer-

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

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, internet access and higher education in the general population, but it is not reported if disparities exist for deaf ASL users nor is it known how severe that knowledge gap may 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' 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 to 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 to 26 years old) were drawn from the HINTS 5, Cycle 1, public dataset using a nationally-representative survey that was administered in 2017.[12] The age of this subset sample was determined based on catchup vaccine eligibility criteria as outlined by the CDC 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 to 26, and men between the ages of 18-21.[8] Males aged 22 to 26 wishing protection and not previously immunized may also receive the vaccination.

For the purpose of the current study, the hearing dataset 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:

HPV knowledge.

Deaf and hearing participants were asked a series of questions related to whether or not they had heard of HPV, understood what HPV stood for and whether or not it can cause cervical, penile, anal, or oral cancers. Additional questions were also included regarding whether or not 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, HSV, 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 participant'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®, or Cervarix®. 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 last 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 both 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 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 healthcare?

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 18-26 years old). Chi-square 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 (BMI), and patient centered communication (PCC). The statistical program SPSS version 25.0 was used for all analyses. Gallaudet University's Institutional Review Board (IRB) approved the study

Results

Sample Description

A total of 235 deaf and 115 hearing adults aged 18 to 26 years old answered all HPV-related questions about whether they had heard of the virus and how successful they felt the HPV vaccine was at preventing cervical cancer. About 45% of the deaf sample had deaf parents. Within each sample, 138 (58%) deaf and 97 (84%) hearing participants had heard of HPV ($p<0.001$).

As shown in Table 1, within the deaf sample, significantly more women (66%) had heard of HPV compared to 48% of male participants. The majority of 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 (see Table 2).

Table 3 displays 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%) compared to the hearing group (29%). While 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 ($p< 0.001$). Both groups did not significantly differ for health insurance coverage and regular provider; however, the hearing group rated their PCC experiences significantly higher than the deaf group did ($p< 0.001$).

Table 4 compares HPV and cancer risk perception between deaf and hearing participants who were vaccine eligible. Hearing participants demonstrated significantly higher accuracy in their risk perception of HPV being linked to cervical cancer than did the deaf participants ($p<0.001$). 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 to deaf participants ($p< 0.01$). Both groups' risk perception for other types of cancer (penile, anal, oral) did not differ. Both deaf and hearing participants reported similar rates of having had a discussion with a doctor or health care professional about HPV vaccine.

Discussion

This national study is the first to explore the knowledge and risk perceptions of deaf young adults regarding HPV, its infectious and neoplastic consequences, and the impact of vaccination on preventing HPV related cancers. Our study supports the hypothesis that deaf young adults who use ASL, when compared to 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. While 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 both deaf and hearing young adult samples gleaned from this study is in the knowledge of HPV's relationship with penile, oral and anal cancers given 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 and risk perception in this population. 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, given that there was no significant difference between deaf and hearing young adults' participation in HPV-related discussion with their doctors, it may 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, making 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 as compared to those not currently enrolled in school, may influence our results in unknown ways given the known impact of educational status on HPV related knowledge.[13] The respondent population may 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 U.S.

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 and developing 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 may 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 may benefit similar at risk populations.

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Acronyms:

ASL:	American Sign Language
HPV:	Human Papillomavirus

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Table 1:

Sociodemographic characteristics of Deaf vaccine age-eligible participants by HPV awareness

		Deaf Young Adults				
		Heard of HPV n=138		**Had not heard of HPV n=98**		
		Mean (SD)		**Mean (SD)**		**p-value**
Age		23 (2.2)		22 (2.4)		**<.01**
BMI[a]		26 (6.6)		26 (6.8)		.42
PCC[b]		62 (23.7)		59 (26.7)		.19
	Subgroups	n	%	n	%	p-value
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%	

		Deaf Young Adults				
		Heard of HPV n=138		Had not heard of HPV n=98		
		Mean (SD)		Mean (SD)		p-value
	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 healthcare 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		

[a] BMI=Body Mass Index

[b] PCC=Patient Centered Communication

Table 2:

Sociodemographic characteristics of Hearing vaccine age-eligible participants by HPV awareness

		Hearing Young Adults				
		Heard of HPV n=97		**Had not heard of HPV n=21**		
		Mean (SD)		**Mean (SD)**		**p-value**
Age		23 (2.2)		22 (2.3)		**<.01**
BMI[a]		25 (5.7)		26 (4.9)		.55
PCC[b]		76 (24.3)		87 (17.8)		.06
	Subgroups	n	%	n	%	p-value
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		

		Hearing Young Adults				
		Heard of HPV n=97		Had not heard of HPV n=21		
		Mean (SD)		Mean (SD)		p-value
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		

[a]BMI=Body Mass Index

[b]PCC=Patient Centered Communication

Table 3:

Sociodemographic characteristics of vaccine age-eligible participants who have heard of HPV

		Group (18 to 26 years old; heard of HPV)				
		Deaf n=138		Hearing n=97		
		Mean (SD)		Mean (SD)		p-value
Age		23 (2.2)		23 (2.2)		**<.05**
BMI[a]		26 (6.7)		25 (5.7)		.22
PCC[b]		62 (23.7)		76 (24.3)		**<.001**
	Subgroups	n	%	n	%	p-value
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		

		Group (18 to 26 years old; heard of HPV)				
		Deaf n=138		Hearing n=97		
		Mean (SD)		Mean (SD)		p-value
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 healthcare provider						
	ASL[c] (direct or interpreter)	73	55.3%	--	--	
	English (written/oral)	58	43.9%	--	--	
	Other	1	0.8%	---	--	
	Missing	6		--	--	

[a] BMI=Body Mass Index

[b] PCC=Patient Centered Communication

[c] ASL=American Sign Language

Table 4:

Risk perception among vaccine age-eligible participants who have heard of HPV

	Deaf n=138		Hearing n=97		
Subgroups	**n**	**%**	**n**	**%**	**p-value**
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 sexually transmitted disease (STD)?					.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 last 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 last 12 months, has a doctor or health care professional recommended that you or someone in your immediate family get HPV shot or vaccine?					.76
No/Not sure	88	77.9%	66	75.9%	
Yes	25	22.1%	21	24.1%	