



Cervical Cancer Patients' Willingness and Ability to Serve as Health Care Educators to Advocate for Human Papillomavirus Vaccine Uptake

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Abstract

Human papillomavirus (HPV) causes nearly all cervical cancer. Only half of females and less than half of males receive the recommended HPV vaccine dose. This study explores whether cervical cancer patients may serve as health advocates to adolescents and their parents in encouraging the uptake of the HPV vaccine. The study targeted an opportunity sample of women seen in the gynecology oncology clinic with a diagnosis of cervical cancer. During interviews, patients were asked about the following: provider conversations regarding cervical cancer, knowledge of HPV and the vaccine, discussions with family or friends about the causes or prevention of cervical cancer, and whether they would be willing to talk with others about the HPV vaccine. Twenty-three interviews were conducted in 2016–2017. Patients ranged from 28 to 61 years of age. Four team members developed a coding list, then used these themes to code the interviews. Six themes resulted from the analysis of the transcripts: (1) Expressions of fears, questioning effectiveness of vaccine; (2) Low level of health literacy; (3) Acquiring health information from television, internet; (4) Provider conversations (with patients regarding HPV and the vaccine); (5) Patient stigma surrounding cervical cancer; (6) Patients' willingness to serve as a health care educator. While cervical cancer patients overall expressed a willingness to serve as health care educators, barriers remain. Low health literacy and a lack of understanding of the causes of cervical cancer persist. These issues will need to be addressed in order for cervical cancer patients to be effective advocates.

Keywords Cervical cancer · HPV vaccination · Education · Survivors

Introduction

According to the American Cancer Society, about 13,240 new cases of invasive cervical cancer will be diagnosed and about 4170 women will die from cervical cancer in the USA in 2018 [1]. HPV is the cause of nearly all cervical cancer and anal cancer as well as some cancers of the vagina, vulva, penis, rectum, and oropharynx. We are interested in assessing general knowledge and attitudes among cervical cancer patients

about the link between human papillomavirus (HPV) and cervical cancer and how the cervical cancer experience has influenced or could influence survivors to promote HPV vaccination among close friends and family members.

While HPV vaccination uptake has progressed in the past decade, HPV vaccine coverage remains lower than the measles, mumps, rubella vaccine (MMR), tetanus, diphtheria, and acellular pertussis (Tdap) vaccine, or varicella vaccine [2]. Beginning in 2006 for females and 2011 for males, the Advisory Committee on Immunization Practices (ACIP) recommended that adolescents aged 11–12 years routinely receive the HPV vaccine. In 2015, 52% of females and 39% of males had received two (or more) doses of the HPV vaccine [2].

There are several pathways to increase knowledge of the vaccine and causes of cervical cancer. Increased and improved provider communication has been demonstrated to be a clear starting point [3–6], but provider communication alone will not address the lack of knowledge particularly among disadvantaged population. Social communication and narrative has

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been demonstrated to be an effective means of communication with this population.

The theory behind our study was to explore if cervical cancer patients would be willing to serve as health care educators, to persuade family and friends to get the HPV vaccine. Perhaps eventually cervical cancer patients could play a similar role in preventing cervical cancer that lung cancer patients have played in preventing lung cancer. In order to discover if cervical cancer patients would be willing to serve as health care educators, we designed a qualitative study to assess their understanding of the disease and its prevention and then assess their interest, ability, and willingness to serve as community educators to speak with parents and to young adolescents about the importance of the HPV vaccination in preventing cervical and other cancers.

Methods

We talked with cervical cancer survivors to understand what they know about their disease: its causes and preventions. We explored the accuracy of their information, from where they gathered their information, and, specifically, their knowledge about the HPV vaccine. Finally, we determined the willingness of these patients to serve as health care educators and advocates for family and friends regarding HPV vaccination.

We used an opportunity sample of women who were being seen in the gynecology oncology clinic for cervical or vulvar cancer. Patients were asked by their gyn-oncologist at the end of their appointment if they would be willing to take part in a short research interview. Interviews were conducted by trained research assistants in a private room in the clinic. Patients were asked if their doctor ever had a conversation with them about the causes or prevention of cervical cancer, if they knew what HPV was, if they knew about the HPV vaccine, what discussions they may have had with family or friends about the causes or prevention of cervical cancer, and whether they would be willing to talk with family or friends about the HPV vaccine. This study received approval from the Geisinger Institutional Review Board. The IRB approved that verbal consent was sufficient for patient participation in the interviews. Informed consent was obtained from all participants included in the study.

Twenty-three interviews were conducted between August 2016 and March 2017. Of the 23 interviews, 15 patients completed a demographic survey. Patients ranged in age from 28 to 61 years of age, with a mean age of 49 (see Table 1). The patients come from a mainly rural area. The majority (8/15) of those who completed a demographic survey indicated that their household income was less than \$35,000. Interviews took an average of about 30 min and patients were provided with a gift card worth \$20 at the completion of the interview.

Table 1 Study respondent characteristics (study $N = 23$)

	49 (28–61)	
	%	N
Average age ($N = 13$)	49 (28–61)	
White	100	15
Hispanic	6	1
Household income ($N = 15$)		
< \$20,000	33	5
\$20,000–\$35,000	20	3
\$35,000–\$60,000	27	4
> \$60,000	20	3
Medical insurance ($N = 15$)		
Public insurance/Medicaid	60	9
Private insurance	40	6
Zip code analysis ($N = 14$)		
90% or greater of the zip code region is rural	64	9
85% or greater of the zip code region is rural	86	12
55% or greater of the zip code region is rural	100	14

Interviews were audio recorded and then transcribed verbatim and de-identified.

We used a grounded theory approach to code and analyze the semi-structured interviews conducted with patients [7]. Grounded theory is a general research method intended to systematically generate categories and theory. The inductive method begins with collecting data; in this instance, patients are interviewed using a semi-structured set of questions that allow for probes so that patients further explain or make connections to other context-relevant information. These interviews were recorded and transcribed. The transcribed documents were read by team members. Four team members read the transcripts multiple times and then developed a preliminary coding list. The study team used the preliminary coding list to code several interviews as a group and refined the coding list into overarching themes. Team members used these themes to code the interviews. Where there were discrepancies in coding, team members discussed the differences to resolve discordance on coding. The initial interview script asked patients to describe their cancer experience. They were asked to explain the origin of their cancer, explanations from providers, and how they have talked about their cancer with family, friends, and others. Finally, these cervical cancer survivors were asked about their willingness to talk about cervical cancer and its relationship to HPV. We use the learning from these conversations to predict the potential barriers and benefits to a survivor model in which cervical cancer providers serve as network educators—promoting HPV vaccination to reduce the risk for cervical cancer.

Results

Six primary themes resulted from the analysis of the transcripts (see Table 2 for details):

1. Vaccine fear—expressions of fear of newness, questioning effectiveness of vaccine
2. Low level of health literacy/understanding of the causes of cervical cancer—explored whether patients seemed to have a clear understanding or not of the causes of cervical cancer
3. Acquiring health information from sources other than medical professionals (e.g., television, internet)
4. Provider conversations or lack of conversations regarding HPV and the vaccine—looked at whether patients had specific conversations with providers regarding prevention of cervical cancer.
5. Patient stigma or lack of stigma surrounding cervical cancer—did patients experience stigma specifically because of the type of cancer they contracted?
6. Serving as a health care educator—did patients express a willingness or reluctance to serve as a health care educator?

Vaccine Fear

When asked for their views on the HPV vaccine, many of the patients expressed concerns regarding vaccines. They also expressed concern regarding how “new” the vaccines were. Some patients did not trust the vaccine. Some did not exactly fear the vaccine, but were dissuaded from vaccinating family members because the vaccine prevented a sexually transmitted disease. Vaccine fear is closely tied to issues with health care literacy which represented a major theme in the comments we received from participants.

Low Level of Health Literacy/Understanding of the Causes of Cervical Cancer

Many patients did not understand the causes of their cancer. Much of the patients’ “understanding” were misconceptions. Furthermore, some patients recognized that they did not understand the causes of their cancer and they had no interest in understanding.

Acquiring Health Information from Sources Other than Medical Professionals

Interestingly, we found that patients were receiving a significant amount of information regarding the vaccine from television commercials. Relying on commercials as opposed to

information from their health care providers is another indicator of low health literacy.

Overwhelmingly, television advertising appeared to be the conduit through which most patients had heard of cervical cancer and/or the various HPV vaccines. Patients also mentioned the internet and pamphlets as sources of information on cervical cancer.

Provider Conversations or Lack of Conversations Surrounding Cervical Cancer

Effective provider communication can be key to addressing misunderstanding and misinformation. While several patients said that they had previous conversations with their provider regarding the causes and prevention of cervical cancer, many patients commented that the first time their provider mentioned causes and prevention was in introducing the research assistant and this study.

Patient Stigma or Lack of Stigma Surrounding Cervical Cancer

Several patients did mention the stigma surrounding this particular type of cancer. Other patients experienced no stigma. The potential for stigma is important to recognize when we make recommendations about how to have conversations about this linkage. It is possible that addressing health care literacy could help with issues of stigma as well.

Serving as a Health Care Educator

When asked about their willingness to serve as a health care educator, the majority of patients expressed an interest in helping prevent others from contracting this cancer. Other patients described how they were already fulfilling this role. Some patients expressed reluctance to serve in that role because of the sexual nature of the disease.

Discussion

Our findings suggest that cervical cancer patients are willing to serve as health care educators and some already have begun to serve in this role. Health literacy may be one barrier to this role as identified by many of the comments made by patients during the interviews. It is possible that this lack of health literacy is potentially related to stigma. We suspect that providers may not have timely conversations with patients about the cause of their cancer because it is not relevant to the treatment, it may be perceived as a sensitive conversation given the age of the patients and the probability that their cancer is caused by a sexually transmitted infection, and the provider may have a stigmatized view of the cause of the cancer. The

Table 2 Themes resulted from the analysis of the transcripts

Theme/subthemes	Representative quotes
Vaccine fear Vaccine is too new	<ul style="list-style-type: none"> • But I also think a lot of these vaccines are in the experimental stages and what do they really do to your body sometimes too? And that is a concern • I don't want to just take everything that comes along so I would question it and I would want to know more about it • I would want to learn more about it but because of what I have been through ... yes I would want more information. I wouldn't want someone else to go through what I went through. If I knew it was 100% cure but if it's just an experimental thing ...
Issue of vaccine preventing sexually transmitted disease	<ul style="list-style-type: none"> • There's nothing to prove to me that if I would've had that shot, I wouldn't have this cancer • Although my family is Catholic and my mom wouldn't have really approved of me getting a vaccine that helped to prevent the spread of an STD so I don't know. • As teenagers, I can honestly sit here and tell you that I knew one of my girls was not sexually active at all. The other one on the other hand had a very steady person in her life and so, it's not that they were out sleeping amongst other people. So in my personal opinion, I probably would not have had my girls vaccinated • People are afraid of vaccines in general and then the added stigma of a vaccine for an STD is a big thing too. And I can think of people in my life who have that type of mindset
Health literacy Not understanding causes of cervical cancer—low health literacy	<ul style="list-style-type: none"> • I don't know why I got it ... it is just something that happened • I think it had something to do with my pH was, was ... changed or something like that • I know is actually passed down. It's hereditary. My mom had cervical cancer, my sister had it, and when they came out and told me I had it, I already knew • I don't want to know nothing. And I don't know nothing. I said I have a son who is a doctor and a daughter who is a nurse. Let them worry about it and that is the way I am with everything
Understanding causes	<ul style="list-style-type: none"> • If I would have been vaccinated then I would not have had it most likely • The more I read and found that it is usually caused by the HPV virus and that that is a viral infection • When they explained it to me, I realized it was probably from the relationships I had and I don't know who they were with, you know? I think I had maybe 8 people
Acquiring health information from sources other than medical professionals	<ul style="list-style-type: none"> • I've seen it in commercials on TV. That's the only education that I have ever seen on it
Lack of provider conversations surrounding cervical cancer	<ul style="list-style-type: none"> • She just brought it up with me today, that's the first I heard of it
Stigma surrounding cervical cancer Patient experiences stigma	<ul style="list-style-type: none"> • Well, it is a little embarrassing, you know what I mean, when they say it is sexually transmitted, you know, because I do feel a little dirty. That maybe I wasn't clean in my choices of who to have a partner with
No stigma experienced	<ul style="list-style-type: none"> • I'm too old for stigma • Everybody that I am surrounded by are pretty logical people and I think that they are very aware that HPV is really common. A lot of people get it and I think they know that, so I think that is why there really hasn't been any negative stigma surrounding it
Serving as a health care educator Willing to be an educator	<ul style="list-style-type: none"> • I have a niece that is 21 so I don't know if she could get it but I will certainly ...and I have coworkers that have teenage daughters and whenever I can with my friends, you know, I can talk to them about it. For sure if it will help prevent someone from getting cervical cancer. I will definitely let them know about it • If I get on Facebook I am going to make sure that I mention to everyone to make sure that you get your kids vaccinated with Gardasil
Already serving as an educator	<ul style="list-style-type: none"> • I have just been telling people to make sure that they get their pap smears often like they should to make sure it gets caught quick enough
Reluctant to be an educator	<ul style="list-style-type: none"> • As long as their parents have them familiarized with their body and stuff like that and that I am not crossing the line • If someone approached and said they wanted information on it I definitely could

correlation between stigma and perceived adherence to treatment recommendation and quality of care and outcomes has been identified in mental health and obesity [8, 9]. Validated instruments to measure stigma continue to be evaluated and may play an important role in any intervention measure to improve provider education.

Health literacy on this topic can be improved with clear and accurate information disseminated at the population level. Promoting survivor conversations, and perhaps using survivors in the media, as used by other cancer prevention campaigns may be one strategy for disseminating the right information to the right people at the right time. Moreover, it is possible that promoting “The Conversation” about the vaccination by young and older women will help to dismiss the wrong perception held by some about HPV. Further, any stigma that remains may be reduced by making the topic more commonplace. The stigma of sexually transmitted diseases (STDs) can be demystified through direct or indirect contact with people affected by STDs, such as cervical cancer patients [10]. Moreover, these conversations may help to remove the “sexual identity” issue that remains when discussing HPV and HPV vaccination, and move it into the realm of cancer prevention.

“Health literacy” represents a set of skills more complex than simply low reading levels. It refers to skills that people need to function effectively in a health care environment, including the ability to read, to understand medication regimens, to use quantitative skills, and to interpret food labels. The 1998 WHO Health Promotion Glossary defined health literacy as “the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions” [11]. Low health literacy has been shown to be strongly linked with lower levels of health screening and immunizations, greater use of emergency care, increased hospitalizations, and poorer health outcomes [12]. More broadly, health literacy is strongly entwined with patient engagement [13] and is a factor in health promotion, both individually and at the population level [14].

Health literacy is important in the prevention of cervical cancer because while survivors may be ambassadors for prevention programming and promotion of the HPV vaccine, they can only be successful ambassadors if armed with accurate information. As seen from the interviews, there is still a significant amount of vaccine fear, as well as overall low levels of health literacy with television advertising serving as a major source of information for this population. Vaccine fear emerges as the result of poor understanding about what the vaccine is, what side effects might emerge, and generally about who is eligible to receive the vaccine. Early in its public health history, the HPV vaccine was linked to concerns from some parent groups about promoting sexual promiscuity among adolescents. There is no evidence that links this vaccine to increases in sexual activity among teens [15]. As with all vaccines, there have been some reports of serious side effects. Side effects such

as a severe allergic reaction are rare [16]. These and other fears can be dealt with quickly and clearly in education associated with promoting the vaccine as a cancer prevention strategy.

Studies have shown that high-quality recommendations from providers to receive the HPV vaccination were strongly associated with HPV vaccination behavior, but only about one third of patients received this type of recommendation [6]. It may be that talking about HPV or cancer is viewed as unnecessary by providers. There are many tasks to accomplish in annual visits and this may be one more thing. Potentially, providers believe that by suggesting the vaccine, their work is done. Conversations in non-medical settings may work to improve uptake and reduce the need for providers to spend a significant amount of time educating their patients.

Previous research has demonstrated the importance of social network contacts in helping women determine their health needs and that it may prove beneficial to incorporate family members and friends when advising patients on cervical cancer prevention activities [17]. Several studies have documented the effectiveness of programs in which cancer survivors encourage cancer screening and cancer prevention activities. One study found that “women who stated that they had heard about the HPV vaccine from a social source were more likely to perceive the HPV vaccine as somewhat or very effective than those without a reported social source of information” [18]. “Larger educational campaigns that highlight the role of social contacts and social recommendation for HPV vaccination merit further study, especially in low-income communities that may face barriers to accessing health information” [18].

Recent public health campaigns (lung cancer, breast cancer) have invoked the power of patient communication with the general public as well as with friends and family members to increase awareness and encourage adoption of preventative measures. These campaigns suggest the importance of using “real people” reporting on real-life experiences as a prevention strategy. These campaigns are only effective, however, in an environment in which patients clearly understand the linkages between the condition of interest and the potential prevention strategies. In March 2012, the Centers for Disease Control and Prevention (CDC) launched its first-ever paid national tobacco education campaign—Tips From Former Smokers. The campaign profiled real people living with the long-term health effects from smoking. The 2012 campaign motivated an estimated 1.64 million smokers to quit and 100,000 smokers to quit for good. Approximately 17,000 premature deaths were estimated to be averted and 179,000 years of healthy life gained [19, 20].

There are many misconceptions and misunderstandings of the causes and prevention of cervical cancer. Two studies based on the Health Information National Trends Survey (HINTS) found clear evidence of these misconceptions. The study based on HINTS 2013 found that while 62% of Americans knew that HPV causes cervical cancer, 34% were unsure and 4% thought that HPV does not cause cervical cancer [21]. Another paper

based on HINTS 2014 found that the majority of respondents did *not* believe that the HPV vaccine is effective at preventing cervical cancer. In general, HINTS illustrates that the knowledge and awareness of most aspects of HPV were low despite ongoing efforts to improve both [4]. This lack of knowledge regarding HPV-related cancers and vaccine was more pronounced within certain disadvantaged populations. HINTS 2013 found that people in rural areas were significantly less likely than those in urban areas to know that HPV causes cervical cancer [21]. HINTS 2014 found that general HPV knowledge, HPV-related cancer knowledge, and HPV vaccine knowledge were influenced by sociodemographic characteristics [4]. This limited understanding regarding HPV and HPV vaccination affects the ability of parents and their adolescent children to make informed choices about HPV vaccination [22]. The poor information creates a barrier to acceptance of the vaccine.

Work will need to be done to overcome the low health literacy of the patients themselves, particularly as the cervical cancer population tends to have lower levels of education and income, which also puts them at risk of low health literacy. We suggest that educating providers about the impact of their perceived stigma will strengthen the effect of provider recommendations of HPV vaccination. Although we have not addressed survivorship in this study, we suspect that the opportunity to share information and experiences may lead to a secondary benefit in the survivor experience of these women.

Compliance with Ethical Standards

This study received approval from the Geisinger Institutional Review Board. The IRB approved that verbal consent was sufficient for patient participation in the interviews. Informed consent was obtained from all participants included in the study.

Conflict of Interest The authors declare that they have no conflict of interest.

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