**Full Length Research Paper**

**Overcoming barriers: the development of an animated film on HPV for deaf and hearing students**

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Deaf youngsters are faced with several types of barriers that preclude them from receiving information, particularly those related to health problems. These difficulties expose this group to unnecessary risks due to their lack of knowledge. The aim of this study was to: 1) identify how aware deaf (>80 dB) people are of Human Papilloma Virus (HPV); 2) develop engaging material to convey information on this subject; 3) evaluate the comprehension and impact of the information given. Initially, a qualitative survey about HPV was undertaken with 42 youngsters from the National Institute for the Deaf in Rio de Janeiro, Brazil, as a result of which their lack of knowledge about HPV became apparent. In aiming to create material related to this subject, we found there was a paucity of videos posted on the topic on the YouTube channel. As a result, we created an animated video about HPV, using stop-motion technique, and which was posted on YouTube. Finally, we conducted a focus group with profoundly deaf students to identify whether they could understand the video. After viewing it, participants showed a significant increase in the understanding of HPV. This study demonstrates that it is possible to develop products in health communication for both deaf and hearing people.

**Key words:** Cancer, human papilloma virus (HPV), animated video, deaf people.

**INTRODUCTION**

**Deafness in Brazil and lack of healthcare information**

There are over five million deaf people in Brazil, ranging from people suffering from slight to profound hearing loss. Deafness is the second largest disability in the Brazilian population. Approximately, 30% of Brazilian deaf people who have severe to profound hearing loss cannot read, while 70% can read Portuguese but have no clear understanding of the language (IBGE, 2012). There is a distinction in Brazil between ranges of deafness, that is, from individuals with severe (more than 70 dB) to profound (more than 91 dB) hearing loss. The first language among the deaf community is Libras (Brazilian Sign Language), which only became official in Brazil in 2005, after a Government decree.

Due to these several communication difficulties, the education of deaf people in Brazil is an enormous challenge. According to the School Census conducted in 2005, there were 66,261 students with profound deafness or milder hearing loss enrolled in Basic Education. In Higher Education, the latest data published in 2004 showed that 974 students have hearing impairment, a clear demonstration that exclusion from school is still a reality experienced by the majority of deaf people.

In light of these obstacles in Brazil and other countries, there are several studies (Folkins et al., 2005; Harmer, 1999; Sadler et al., 2001; Shabaik et al., 2010; Yao et al., 2011; Zazove et al., 2009) on the barriers that the deaf community faces in accessing health information, which make them vulnerable to unnecessary risks due to a lack of adequate information on prevention and healthy lifestyles. There is a need to overcome these barriers through efforts aimed at a closer interaction between health and education, bridging the gap that hinders greater accessibility. Furthermore, the interactions between doctors and deaf patients cannot always rely on interpreters (Tamaskar et al., 2000), and as such degenerates (Zazove et al., 2009). Reasons for this may be related to language, the isolation of the deaf...
community itself and difficulty in absorbing media reports (Schiaffino and Rumjanek, 2012).

**HPV: Lack of knowledge generates more cases**

Infections transmitted through unprotected sex, such as the Human Papilloma Virus (HPV), are very common worldwide, with a higher prevalence in young women aged between 20 and 46 years in many countries (Ho et al., 1998; Rama et al., 2010; Teixeira et al., 2002). A survey conducted by the Brazilian National Cancer Institute (INCA, 2012) indicates that about 25% of Brazilian women are infected with the virus. Approximately, three to five percent of the sexually active population has symptoms of the disease, and the detection of HPV has grown by 500% in Brazil in the last decade (Queiroz et al., 2005). Several studies have shown that the population of developing countries has a limited knowledge of HPV. Most people know it is a sexually transmitted disease, but they are unaware of its association with cancer (Ackerson et al., 2008; Vanslyke et al., 2008), and this, seemingly, is also the case in Brazil (de Sousa et al., 2008; Doreto and Vieira, 2007), where the majority of the women surveyed had never heard of HPV. Between 1999 and 2005, a survey using data from the Integrated Cytopathology Service in the National Institute of Cancer (INCA) showed a 2.6 times increase in cervical abnormalities in adolescents aged 10 to 19 years (Pedrosa et al., 2008), pointing to the urgent need for developing communication strategies aimed at that particular audience.

While HPV lesions are increasing among young hearing people because of a small number of reasons combined with lack of adequate information, in what state is the awareness level of the Brazilian deaf community about HPV and its correlation with cancer? Are products conceived on this theme able to sensitize this audience?

This study aims to: (a) investigate knowledge about HPV in a group comprising young Brazilian deaf people; (b) identify a health communication tool able to reach this audience; (c) create and develop an engaging product addressing the issue of HPV; and (d) evaluate if it can be understood by this group of young people.

**METHODOLOGY**

**Evaluation of knowledge about HPV**

To ascertain the level of knowledge about Human Papilloma Virus (HPV) in a group of young deaf students, we asked them to answer a semi-structured questionnaire. The group was composed of 42 severe to profound (more than 80 dB) young deaf students, aged between 15 to 22 years old, from the National Institute for the Deaf, located in Rio de Janeiro, Brazil. Among the participants, one had completed elementary school, 33 had completed high school, seven had an incomplete higher education and only one had a higher education degree.

We developed a semi-structured questionnaire with three open questions, and we relied on the collaboration of three interpreters/ translators who helped participants to understand the questions, but were asked not to interfere in the answers. The questions were as follows:

- What is HPV?
- How is it transmitted?
- What can HPV cause?

The majority of the deaf volunteers (28 individuals, or 66.6%) failed to answer any question. Only eight had a vague idea that HPV is a disease, although, not responding clearly. Six others conveyed the concept that HPV is a virus, despite also not responding clearly.

In relation to sexual transmission, only five showed some understanding about the contamination route, and only one said clearly that the "route of transmission is sexual." One respondent said that contamination occurs through blood, and 35 did not answer this question.

None of the participants could explain the consequences of HPV. It is important to mention that 34 young people wrote, "I do not know." One respondent said "disease" and another mentioned "death", but also "itching and fever". The other six did not answer.

**Evaluating HPV information available on Youtube**

Based on the findings described earlier, from which it became clear that the young deaf community ignore the problems posed by HPV infection, we analyzed videos about HPV on YouTube – the Internet channel created to enable the posting of videos up to 15 min in length because the Internet is widely used by the deaf community (Jones et al., 2010).

To do this, we undertook both a quantitative and qualitative analysis of the content found on this channel. The quantification was performed by using the "keywords" function in YouTube’s search engine. This tool allows complex searches in which one can associate a set of required keywords to a subset where at least one of the words should be discriminated. This feature allowed us to seek, for example, videos in the description of which the keywords “HPV” and “cancer” must either appear, or be associated with the keyword "sex", "sexually", or both.

This search tool enables separating of videos produced in Portuguese or in any other language. We did not employ other filtering possibilities such as duration, category, relevance and time of recording.

Films on HPV, in Portuguese or in English, were initially analyzed, one by one, to determine the technology used; its purpose and public acceptance, with the latter based on the number of hits and comments (Table 1).
Table 1. Films on HPV and Cancer available on YouTube, in Portuguese or in English.

<table>
<thead>
<tr>
<th>Keyword</th>
<th>English/occurrences</th>
<th>Portuguese/occurrences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>116,000</td>
<td>2,150</td>
</tr>
<tr>
<td>HPV</td>
<td>1,590</td>
<td>57</td>
</tr>
<tr>
<td>Cancer + HPV</td>
<td>324</td>
<td>11</td>
</tr>
</tbody>
</table>

Thereafter, only videos available in Portuguese on the subject of HPV were evaluated, since this project is aimed at young audiences in Brazil. Of the 57 videos analyzed, approximately, 23% were not applicable to the topic of HPV. Another 33% were video interviews with experts or news stories made for television, dealing with the HPV and cervical cancer topics. 21% were produced by schools, consisting of plays or exhibitions on video or slides on the subject. The remainder was videos from HPV prevention campaigns, commercial films about the vaccine or novel scenes with prevention campaigns to combat the virus. Animation techniques were used only in the HPV vaccine promotional video, although, in a very incipient way.

The video with the largest number of hits (76,265) was one with an appealing subtitle ("The worst video on YouTube"), consisting of a small slide show (25 s) with shocking photos of mouth cancer. The second most viewed video, with 20,710 hits, was school work, in which teenagers performed a comedy act about HPV issues. The third most viewed video (9,747) featured a narrative on a slideshow presentation.

Apparently, there is no link between the quality of a video production and the number of visitors. Rather, it is the most appealing videos that tend to have a greater number of visitors.

**Animated video development**

Because of the paucity of videos on HPV, we developed an animation script and a storyboard that could be understood by both young deaf people and listeners. We used the stop-motion technique. This technique consists in photographing frame by frame, and then editing the images using a computer program. The characters were created and developed in clay and miniature sets were built. The final product was released and can be accessed in http://www.youtube.com/watch?v=OlHkBjBrvSwI.

We chose a simple script that shows the romantic relationship between a penis, the Pintoso and a vagina, Gina. In addition to the protagonist, we also created a physician Doctor, Esteto Scopio (in English, Dr. Stetho Scope) and a condom. The video entitled ‘Love’ in times of HPV features a story that unfolds in Rio de Janeiro, at Copacabana beach, where the protagonists have a casual meeting. After sexual intercourse without using a condom, Gina showers and recalls the scene, thinking about the risks of being contaminated. Concerned, Gina goes to Doctor Esteto Scopio and, in simple speech balloons, like those used in comic books, there is anatomical information given for two bodies, one female and one male. Red signals appear to identify the risk of cancer of the mouth, larynx, lung and genitals, and ask how the virus spreads: through sex, blood, and placenta. The Doctor tells her that she needs to have a curettage procedure. Gina and Pintoso met again at Copacabana beach. They return to the bedroom and Gina only accepts intercourse for this second time with use of a condom. The three minutes film ends with Gina, Pintoso and the condom in bed, wrapped in a quilt. After this scene, a Brazilian Sign Language performer appears and relates three sentences:

1. HPV is a virus that can cause cancer
2. Consult your gynecologist or urologist regularly
3. Always use a condom.

These phrases are then translated into Portuguese, English, Spanish, German and French.

**Focus group with deaf people**

In order to complete the investigation, we used the focus group technique, gathering a group of young deaf people (Bisol et al., 1999). The group consisted of six youngsters, three boys and three girls, all profoundly deaf (>91 dB), aged between 17 to 20 years old. Only one of them could read in Portuguese. All of them communicate using Brazilian Sign Language.

The focus group participated in the presentation of our animated film ‘Love’ in HPV Times, and after that, a discussion was held about what they thought of the material and our strategy. The focus group technique has gained prominence initially in market research and advertising (Merton et al., 1990). More recently, it has also been used by the social sciences, but this technique is rare with deaf people (Bisol et al., 2008). The use of focus groups can lead to rich discussions, but they must be very well prepared when applying the technique to people with disabilities. These concerns should include the recruitment strategy, who to include in the research, activity planning, the number of participants, the appropriate training of the moderator who will conduct the debate, the work of the sign language interpreter, the type of recording, and analysis of results (Kroll et al., 2007).
In our study, participants were asked to sit in a semi-circle in front of a computer. A Brazilian Sign Language (Libras) interpreter accompanied the whole process and reported, alongside the video transmission, what comments they made. A discussion about their perception of the video content was initiated and their opinions were sought. The whole process was videotaped, and some relevant aspects were noted by the researchers involved. The purpose of this focus group was to examine a sample of the deaf community derived from the National Institute for the Deaf, and their opinions about this product as a health communication strategy.

The volunteers were invited to participate in the research and were informed about the purpose of this study being with regard to health issue, as well being reassured about the protection and confidentiality of their personal data. The study protocol was approved by the Ethics Committee of the National Institute for Public Health, Federal University of Rio de Janeiro (CEP / IESC-UFRJ).

**FINDINGS AND DISCUSSION**

**What do deaf people know about HPV?**

It was clear from our results that the small group of severely/profoundly deaf young people that responded to our questionnaire had little notion of what HPV was and what it could cause. This was not surprising as in another study with a sample consisting of 391 hearing young people where we found a similar result (unpublished observations). This is in accordance with what has been reported by other groups in Brazil (de Sousa et al., 2008; Doreto and Vieira, 2007). Nevertheless, as stated before, Brazilian deaf people have little knowledge even of much better known subjects such as HIV (Bisol et al., 2008).

In a survey, we conducted to investigate the Brazilian advertising campaigns developed around the theme of HPV and we found only nine national and seven statewide campaigns in 2008 and 2011.

Starting from the assumption that YouTube is a cultural medium able to reflect society’s interests and concerns regarding the various issues that afflict it, we realized when analyzing the data from this survey that little interest is shown in the issue of HPV, despite its importance for public health.

Of the 116,000 videos about cancer in all languages, we found that only 1.37% considered HPV as a risk factor for cancer. For videos in Portuguese, the percentage seemed to be slightly more favorable for the "HPV" word: 57 out of 2,150, or 2.65%, but we identified that a considerable proportion (23%) were not applicable because they had been produced as schoolwork. Based on these data, we found that in both cases, video production is very low relative to the total amount of videos about cancer.

**Overcoming barriers: A focus group with deaf people**

The six deaf people that participated in the focus group attended an extension course in science at the Federal University of Rio de Janeiro. They were invited to watch the video, knowing that this study aimed to determine their understanding of a health issue. The research theme was not disclosed.

The young people recruited had profound deafness and preferred to communicate using the Brazilian Sign Language, Libras. Immediately after the video started playing, they started to comment:

Deaf girl: “a penis and a vagina”.
Deaf boy added: “Condoms to avoid problems”.
Another young boy: “One might get ill or become pregnant. Then will regret”.
When they saw the image of the virus, they commented:

“Oh, look there is a virus. There were changes in cells”.

Another participant comments that it seems like a kind of infection:

Deaf girl: “It will spread”.
A participant says it is HIV. When the character Gina starts showering, a deaf boy says:

“Now she is feeling guilty”.
Another participant: “Poor thing, you have to go to the doctor”.

At the end of the video, we started the discussion. They said they understood that the "man" was sick.

Deaf boy: “I thought it was AIDS, but it is HPV. What is it? How is it?”

As noted by Harmer (1999), the deaf community has only rudimentary knowledge about human sexuality, methods of protection against disease and birth control. They also have limited access to sex education programs. Although, these young people attended an extension course on science and have knowledge about Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS), they demonstrated that their lack of knowledge about other sexual issues is still significant and persistent.

After these initial questions, they narrated the video story again in detail: sex without condom, a visit to the doctor, Gina receiving guidelines in an appointment with Doctor Esteto Scopio, and how to use condoms in order to prevent a partner from disease. They added that the female character guided the male character in understanding the risk of contamination with sexually transmitted diseases such as AIDS. In sequence, the interpreter reported the conversation of the participants:
Deaf girl: “She advised him to use condoms and avoid HPV”.
Another girl: “They met; she did not even know what was going on with him, his life conditions, and his health. They made love without condoms. In a second meeting, even though he did not want to, she made a point of using condoms. The vagina went to the doctor; she was advised that the penis should use a condom. It was an initiative of ‘woman’”.

A deaf boy added: “He did not use condoms because he had no guidance. He did not have enough information”.
Deaf girl: “Condom use is good for both, but the man is very stubborn. And it does not take away sexual attraction and lust at all. So you need to use condoms, partly to prevent AIDS. With or without condoms, the relationship continues with the ‘same taste’”.
Deaf boy: “We saw the cellular changes that can cause cancer”.

Deaf girl: “Other diseases too, not just cancer. AIDS and a range of diseases that can bring trouble …” When asked whether they had previously been given information on HPV, they said they had seen a quote about the virus, but no deeper explanations.

Deaf girl: “HIV is already known, but not HPV: the acronym is unknown and the disease also. We are receiving information on this disease for the first time”.
Deaf boy: “The video shows the altered cells and can cause cancer. It was very clear”.

They then started talking about viruses and DNA alterations.

These comments illustrate what Moscovici (2000) treats as being “social representations”, or which are “representative of the opinion movements or social positions” on an issue. The young participants in this study were aware of the risks of unprotected sex, and knew about the risks of HIV and AIDS, and virus transmission through sexual contact. These data corroborate the studies by Bisol et al. (2008) and Goldstein et al. (2010), although, these authors point out that deaf people have less knowledge of HIV compared to hearing people. The difference in our study is that it is related to HPV. We verified that the Brazilian deaf community has no proper understanding of the virus and its association with cancer.

“Specifically, it is to identify, on one hand, what appears literally, and secondly, what emerges from the constructive discussions and presents adaptive processes, indexes of social and cultural changes” (Moscovici, 2000: 246).

At the end, very excited, they concluded that “the animation was very good, clear”, showing “her regret”.

Deaf boy: “Very nice. 100%”.

Another young boy: “Much easier to understand”.

They suggested that, when presenting the importance of condom use, the message should be more imperative, and that when the interpreter appears in the final scenes of the video, the sentences in Libras should be sequential, without a pause. At the end, they asked for the link to our video on YouTube in order to disseminate it among their deaf friends.

It was interesting to note that, as already mentioned by de Sousa et al. (2008), many deaf as well as hearing people had never before been exposed to information about HPV. Moreover, they associate HIV with HPV.

This focus group was conducted over a short time so as not to cause boredom or fatigue in the participants. An aspect emphasized by Kitzinger (1994) is the importance of forming focus groups of participants who preferably already know each other, because this strategy facilitates interaction and prevents participants from feeling shy or embarrassed about making comments that may contain conceptual errors or discussing issues that are taboo, such as sex. In our activity, we realized that if participants already know each other, then, the discussion flows even when they are dealing with a subject such as sex. The participants expressed themselves freely and, unlike the study of Bisol et al. (2008), there was more effective participation between women compared to men. Another aspect highlighted by Kroll et al. (2007), which is of fundamental importance for us, is the training and participation of the Brazilian Sign Language interpreter. He or she needs to be skilled in conducting the discussion, while refraining from interfering with the results emerging from the group itself. Bisol et al. (2008) addresses this issue, because the “translation” of Libras into Portuguese has certain limitations and may affect the sequential analysis of the structure of “dialogue” between the deaf participants, so that there may be an interpretation rather than a “translation”.

In our study, the interpreter who participated in the activity had constant contact with the young deaf people. We believed that this proximity also assisted in overcoming potential barriers, eliminating taboo subjects, increasing the debate and contributing to the free expression of the participants and information exchange.

LIMITATIONS

This study was based on a qualitative questionnaire issued to 42 deaf students of the National Institute for the Deaf; this led to the development of a health communication product dedicated to the theme of HPV that was then analyzed using a focus group of six young deaf people enrolled in an extension course in science. The number of participants that answered the qualitative questionnaire was limited and the young people from the focus groups received scientific information in a manner
that was different from traditional teaching methods. Although, this sample may not be representative of the deaf community, as participants had received a certain amount of general scientific knowledge, we believe that the results of the discussions are relevant and can support future projects. We are also aware that an analysis of the understanding of a product for a specific group does not mean that this same group will retain this knowledge for a long period. It is important to monitor educational interventions and communications in health over a longer period of time. Despite these limitations, the lively debate among the deaf participants has brought us hope that health communication strategies can be developed smoothly and can be understood both by deaf and hearing young people.

CONCLUSIONS

Although, many programs for deaf education, aiming to conquer new frontiers, have been produced in recent decades, solutions have been tentative and disparate, especially, in Brazil.

The importance of our study, as well as, others (Golos, 2010), is that the results highlight valuable topics for future consideration by specialized professionals in health communication, thereby, contributing to the process of greater inclusion of the deaf community. On the basis of this project, we realized that by considering actions and information strategies, it is possible to create products that meet both the needs of the general population and deaf people, without using captions or "windows" with interpreters.

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