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Article

Head and Neck Cancer in Pan-American Notable People: An International Survey

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Abstract: Background: The study of notable people as agents for increasing cancer awareness started just in the last decades of the 20th century. This study aimed to identify Pan-American notable people with head and neck cancer (HNC) and to assess HNC's professional perspective on communicating stories of notable patients with HNC to promote prevention. Methods: This cross-sectional study was conducted by applying a RedCap questionnaire to oral medicinists, oral pathologists, head and neck surgeons, and clinical oncologists with experience in HNC research, education, or treatment in Pan-American countries. Additionally, a structured search was performed on PubMed, Scopus, EMBASE, Web of Science, LILACS, and gray literature Results: We identified 42 notable people from the United States, Brazil, Argentina, Mexico, El Salvador, Chile, Colombia, and Peru who were mainly actors, athletes, and musicians. Participants agreed that stories of notable patients with HNC can positively impact the population and promote prevention if communicated by the internet, social media, and television. Conclusion: In the Pan-American region, notable individuals who have suffered from HNC may be powerful advocates for increasing cancer awareness and promoting prevention strategies. The professionals involved in the study expressed a positive inclination towards using the stories of these notable HNC survivors as an effective prevention strategy.

Keywords: head and neck cancer; oral cancer; prevention; famous people; celebrities; public awareness

1. Introduction

Head and neck cancer (HNC) comprises a heterogeneous group of tumors and represents the sixth most common cancer in the world. According to GLOBOCAN 2020, the number of new oral cavity, larynx, and oropharynx cancers in the world was estimated at 660,740. [1–3] While the prevalence of HNC differs among countries, the Pan-American Health Organization (PAHO) region is known for its high incidence rates, particularly in the United States, Brazil, and Cuba with higher mortality rates in Brazil, Cuba, and Uruguay within the region. [4] Apart from skin and thyroid tumors, the majority of HNC cases (over 90%) consist of squamous cell carcinomas (SCCs). [5–7] Risk factors include exposure to tobacco-derived carcinogens, and excessive alcohol consumption. Increasingly, tumors that arise in the oropharynx are linked to prior infection with high-risk Human Papillomavirus (HPV) infections, primarily HPV-16. [5,6,8–10] Therefore, a significant portion of HNCs could be prevented by reducing the exposure to risk factors and implementing widespread HPV vaccination programs. [6]

In general, more than 60 % of patients with HNC are diagnosed with clinical stages III or IV, this carries a higher risk of locoregional recurrence, distant metastasis, and treatment failure, leading to high mortality rates. [5,6,9] Since oral-cavity cancers are easily accessible to visual inspection and are often preceded by clinically evident oral potentially malignant disorders (OPMDs), there are opportunities for early detection through screening. [11]

Public interest in health issues may rise if a celebrity becomes affected by a disease. [12] The interest in the study of celebrities started in the last decades of the 20th century and developed in the 21st century. [13] Celebrities (also known as notable people) are usually individuals with some notability index and influence on their field of activity. [14] They often emerge from the entertainment and sports industries, but different professions also have the power to influence a large number of people [13] and this wide recognition may be used to promote more publicity about the risk factors, signs, and symptoms of HNC. [15]

Therefore, understanding the relevance of notable people and their potential influence on public interest in health issues such as HNC is extremely important. Thus, this study aimed to identify Pan-American notable people with HNC and to assess professional perspectives about communicating stories of notable patients with HNC to promote prevention.

2. Materials and Methods

This study was conducted using an online survey, which was distributed among professionals specializing in Oral Medicine, Oral and Maxillofacial Pathology, Head and Neck Surgery, and Clinical Oncology across Pan-American countries. Furthermore, a structured review was conducted to identify relevant literature documenting notable individuals with HNC from the Pan-American region.

2.1. Survey

2.1.1. Ethical Considerations

The corresponding protocol for the cross-sectional study was approved by the Research Ethics Committee of the Piracicaba Dental School (CAAE: 58068822.1.0000.5418) and conducted according to the Declaration of Helsinki. All participants sign a digital informed consent form before entering this study.

2.1.2. Instrument

A self-administrated questionnaire was designed in REDCap (Research Electronic Data Capture) in Spanish and English. The questionnaire was structured in 3 sections as follows: sociodemographic and professional characteristics (age, gender, country where they currently work, profession, level of academic training obtained, and number of patients treated per week), known notable patients with HNC, and professional perspectives. The question format was designed using categorical choices.

2.1.3. Participants and Sampling Strategy

The study used non-probability sampling. The eligibility criteria included professionals in Oral Medicine, Oral and Maxillofacial Pathology, Head and Neck Surgery, and Clinical Oncology working in the Pan-American countries. Exclusion criteria comprised incomplete questionnaires. A list of professionals that meet eligibility criteria was created after contacting the Iberamerican Academy of Oral Medicine and Oral Pathology. Then, participants were invited via e-mail, and those who accepted participation got a link (<https://redcap.link/vwekjsf5>) that redirected them to the informed consent form and questionnaire. The period of data collection was between 09 January to 29 June 2023.

2.1.4. Data Collection and Analysis

Qualitative and quantitative data were tabulated and processed in Microsoft Excel®. Further narrative analysis was performed by descriptive statistics using mean values, absolute numbers, and percentages.

2.2. Literature review

2.2.1. Information sources and search strategy

Individual electronic search strategies were performed on April 19th, 2022, and updated on 27th May 2023. The search strategies were done for the following databases: PubMed, Scopus, EMBASE, Web of Science, and LILACS, without period restriction. An additional search in the gray literature including Google Scholar, ProQuest, and “Biblioteca Digital de Teses e Dissertações (BDTD), Brazil” was performed (**Supplementary Table 1**) to identify publications regarding Pan-American notable people with HNC.

2.2.2. Eligibility criteria

Articles were included if they met all the following criteria: 1) Publication about Pan-American notable people of any age diagnosed with HNC, defining “notable people” as researchers, physicians, scientists, inventors, journalists, actors, writers, musicians, filmmakers, politicians, activists, revolutionaries, businessmen, and athletes were included. 2) English, Portuguese, or Spanish language. Exclusion criteria were as follows: (1) Unavailable full text, (2) publication with non-specific localization of cancer.

2.2.3. Selection process

Following the initial search, two independent reviewers performed the selection in two phases (JMR and MEPO). In the first phase, publications were selected by screening titles and abstracts using online software (Rayyan, Qatar Computing Research Institute). Publications that met the inclusion criteria were read in full text to assess eligibility. Divergences at any phase were resolved by a common consensus among the authors.

2.2.4. Data collection and statistical analysis

Clinical and sociodemographic information from the identified notable HNC characters were collected, such as name, gender, occupation, country, anatomical site of cancer, year and age at diagnosis, risk factors, signs, and symptoms before the diagnosis. The list of notable people was grouped by country. Data collected were tabulated and processed in Microsoft Excel®, and further narrative analysis was performed by descriptive statistics using absolute numbers, and percentages.

3. Results

3.1. Selection process

The search identified 1,972 records from the databases, and 445 additional from gray literature. A total of 2,417 records were retrieved. In the first phase, 415 duplicates were removed, leaving 2,002 to be screened by titles and abstracts. In the second phase, 47 publications that met the inclusion criteria were read as full text to assess eligibility. A total of 22 publications were selected corresponding to 9 articles, 1 letter to the editor, 3 editorials, 3 obituaries, and 6 newspapers. Additionally, 3 articles from the screened reference list were included. The selection publication process is presented in the flowchart (**Figure 1**). The list of included publications is available in **Supplementary References 1**.

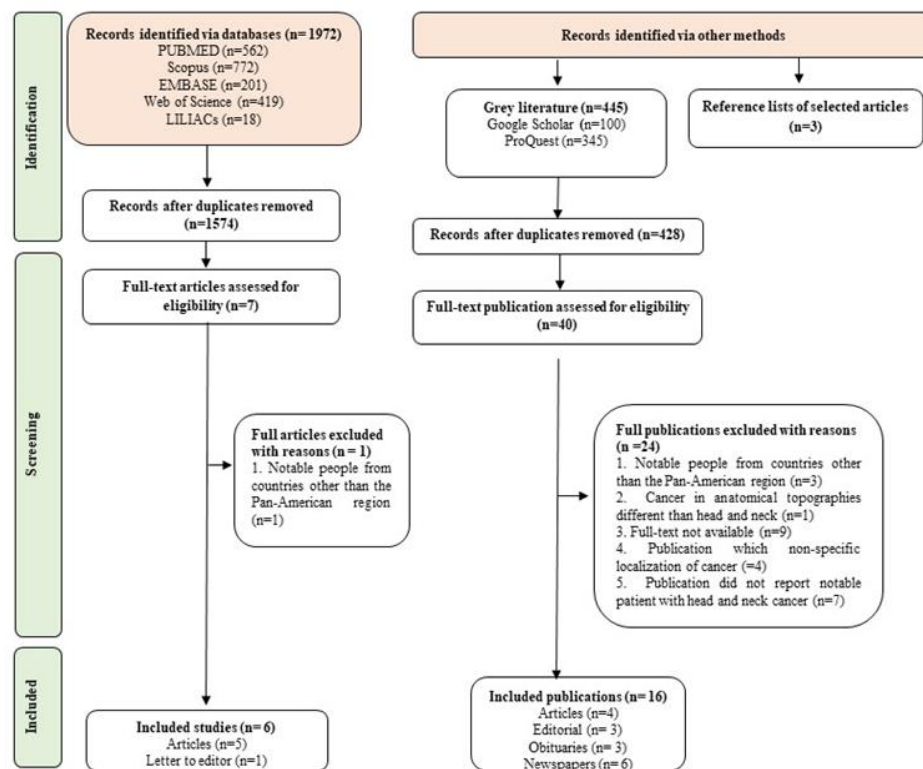


Figure 1. Flowchart illustrating the literature search and study selection.

3.2. Notable people

A total of 18 notable people were identified from the survey (**Supplementary Table 2**) and 29 from the structured research (**Supplementary Table 3**). After removing five duplicate names from the two above sources, a total of 42 notable people were collected from the United States (29, 69.0%), Brazil (4, 9.5%), Argentina (3, 7.1%), Mexico (2, 4.8%), El Salvador (1, 2.4%), Chile (1, 2.4%), Colombia (1, 2.4%), and Peru (1, 2.4%). Of these, 35 (83.3%) were male and 7 (16.7%) were female. Regarding their occupation, actors (15, 35.7%), athletes (6, 14.3%), and musicians (6, 14.3%) were the most identified (**Table 1**).

Table 1. Pan-American notable people diagnosed with head and neck cancer.

N	Name	Gender	Occupation	Country	Anatomical site of cancer
1	Ulysses Simpson Grant	M	President	United States	Oral cancer
2	Grover Cleveland	M	President	United States	Oral cancer
3	Babe Ruth	M	Baseball player	United States	Nasopharyngeal cancer
4	Jack Klugman	M	Actor	United States	Laryngeal cancer
5	Ed Sullivan	M	Television host	United States	Oropharyngeal cancer
6	Sammy Davis Jr	M	Singer, dancer, and actor	United States	Laryngeal cancer

7	Mary Esther Wells	F	Singer	United States	Laryngeal cancer
8	Robert B. Polhill	M	Business professor	United States	Throat cancer
9	Lana Turner	F	Actress and model	United States	Throat cancer
10	Bill Tuttle	M	Baseball player	United States	Oral cancer
11	Brett Butler	M	Baseball player	United States	Throat cancer
12	George Harrison	M	The Beatles' lead guitarist	United States	Throat cancer
13	Edie van Halen	M	Rock musician	United States	Tongue cancer
14	Michael Douglas	M	Actor and producer	United States	Oropharynx HPV-mediated (p+16)
15	Rusell Means	M	Actor	United States	Oral cancer
16	Val Kilmer	M	Actor	United States	Laryngeal cancer
17	William Hanna	M	Animator and cartoonist	United States	Laryngeal cancer
18	Kirk Collins	M	Football player	United States	Throat cancer
19	Jon M. Huntsman	M	Billionaire industrialist	United States	Oral cancer
20	Mike Evans (Lionel Jefferson)	M	Actor	United States	Throat cancer
21	Thomas K. Washington	M	Businessman and spokesperson against racial prejudice	United States	Throat cancer
22	Khaterine Hepburn	F	Actress	United States	Oropharyngeal cancer
23	Jonh Steele	M	Paratrooper	United States	Laryngeal cancer
24	Roger Ebert	M	Film reviewer	United States	Salivary gland cancer
25	Dexter Keith Gordon	M	Jazz musician	United States	Laryngeal cancer
26	Amanda Blake	F	Actress	United States	Throat cancer
27	Lon Chaney	M	Actor	United States	Throat cancer
28	Grant Achatz	M	Chef	United States	Lip and oral cavity
29	Stanley Tucci	M	Actor	United States	Lip and oral cavity
30	Luiz Inácio Lula da Silva	M	President	Brazil	Larynx
31	Heloisa Pericé	F	Actress	Brazil	Minor salivary gland oral cavity
32	Branco Mello	M	Singer	Brazil	Hypopharynx
33	Guilherme Lemos	M	Researcher, artist	Brazil	Oropharynx HPV-mediated (p+16)
34	Juan Jose Antonio Castelli	M	President	Argentina	Lip and oral cavity
35	Gustavo Garzón	M	Actor	Argentina	Lip and oral cavity
36	René Houseman	M	Footballer	Argentina	Tongue cancer
37	Irma Lozano	F	Actress	Mexico	Major salivary glands
38	Lázaro Cárdenas	M	President	Mexico	Skin
39	Roberto D'Aubison	M	Politician	El Salvador	Larynx
40	Pablo Krögh	M	Actress	Chile	Lip and oral cavity
41	Martha Liliana Ruiz	F	Actress	Colombia	Lip and oral cavity
42	Alberto Fujimori	M	President	Peru	Lip and oral cavity

3.3. Professional’s perspectives

A total of 25 participants with experience in research, education, or treatment of HNC from 16 countries in Pan-America answered the entire questionnaire (**Supplementary Table 4**). Of these, 13 (52.0%) were females, and 12 (48.0%) were males with a mean age of 45 years, ranging from 32 to 82 years. Twenty-three (92.0%) were dentists and 2 (8.0%) were physicians. Fourteen (56.0%) had some training in Oral Pathology, 13 (52.0%) in Oral Medicine, 1 (4.0%) in Head and Neck Surgery, 1 (4.0%) in Clinical Oncology, and 1 (4.0%) did not have any formal postgraduate preparation (**Table 2**).

Table 2. Sociodemographic characteristics of the survey’s professionals (n=25).

Characteristics	n (%)
Age	
Mean	45 years
Range	32 -82 years
Gender	
Female	13 (52.0%)
Male	12 (48.0%)
Country	
Mexico	4 (16.0%)
Argentina	2 (8.0%)
Chile	2 (8.0%)
Colombia	2 (8.0%)
El Salvador	2 (8.0%)
Peru	2 (8.0%)
United States	2 (8.0%)
Brazil	1 (4.0%)

Canada	1 (4.0%)
Costa Rica	1 (4.0%)
Ecuador	1 (4.0%)
Guatemala	1 (4.0%)
Honduras	1 (4.0%)
Paraguay	1 (4.0%)
Uruguay	1 (4.0%)
Venezuela	1 (4.0%)
Profession	
Dentist	23 (92.0%)
Physician	2 (8.0%)
Specialist	
Oral Pathology	8 (32.0%)
Oral Medicine	6 (24.0%)
Head and Neck Surgery	1 (4.0%)
Oncologist Clinic	1 (4.0%)
Master's Degree	
Oral Pathology	5 (20.0%)
Oral Medicine	3 (12.0%)
Doctorate Degree	
Oral Pathology	5 (20.0%)
Oral Medicine	8 (32.0%)
Does no formal postgraduate preparation	1 (4.0%)
Number of patients treated per week	
Does not treat	2 (8.0%)
Less than 5 per week	16 (64.0%)
5 or 10 per week	1 (4.0%)
15 to 20 per week	1 (4.0%)
More than 20 per week	1 (4.0%)
Does not known	0 (0.0%)
Prefer not to answer	4 (16.0%)

Among participants, 13 (52.0%) reported knowledge about 1 to 4 Pan-American notable patients diagnosed with HNC whose case was covered by the media. Participants found out about the notable persons' diagnoses mainly through the internet (8, 32.0%), television (8, 32.0%), their own clinical practice (4, 16.0%), and friends, colleagues, or relatives (4, 16.0%) (**Table 3**).

Table 3. Information about notable people known by the professionals.

Questions	n (%)
Do you know any Pan-American notable patient with current or previously diagnosed head and neck cancer whose case was covered by the media? (n=25)	
Yes	13 (52.0%)
No	12 (48.0%)
How many? (n=13)	
1	5 (38.5%)
2	5 (38.5%)
3	2 (13.4%)
4	1 (7.7%)
>4	0 (0.0%)

How did you find out about the notable patient's disease? (n=25)

Internet	8 (32.0%)
Television	8 (32.0%)
Friends/colleagues/relatives	4 (16.0%)
Social media	1 (4.0%)
Scientific literature	0 (0.0%)
Radio	0 (0.0%)
Newspapers	0 (0.0%)
Other*	4 (16.0%)

The majority of participants (24, 96.0%) agreed that communicating stories of notable people diagnosed with HNC can promote primary prevention by reducing risky behaviors, and all the participants (25, 100.0%) agreed that communicating stories of notable people diagnosed with HNC can promote early detection of HNC mainly through the internet (22, 91.7%), followed by social media (20, 83.3%) and television (20, 83.3%) (**Table 4**).

Table 4. Evaluation of the perspective of professionals about communication of stories of notable patients with HNC to promote prevention (n=25).

Questions	n (%)
Communicating reported stories of notable patients diagnosed with head and neck cancer can have a positive impact on the population and promote primary prevention by reducing risky behaviors	
Yes	24 (96.0%)
No	0 (0.0 %)
Does not know	1 (4.0 %)
Does not answer	0 (0.0 %)
Communicating reported stories of notable patients diagnosed with head and neck cancer can have a positive impact on the population and promote early detection by encouraging seeking professional care for evaluation	
Yes	25 (100%)
No	0 (0.0 %)
Does not know	0 (0.0 %)
Does not answer	0 (0.0 %)
The population's generated impact by news of cancer diagnoses of notable patients is short-lived	
Yes	10 (40.0%)
No	5 (20.0%)
Does not know	10 (40.0%)
Does not answer	0 (0.0%)
Dissemination of information about head and neck cancer in relation to the diagnosis of notable patients can be done by:	
Internet	23 (92.0%)
Social media	21 (84.0%)
Television	21 (84.0%)
Educational lectures in healthcare centers	17 (68.0%)
Educational campaigns	15 (60.0%)
Educational videos in healthcare centers	15 (60.0%)
Newspapers	15 (60.0%)
Educational programs in dentistry schools	14 (56.0%)
Dentists	13 (52.0%)
Radio	13 (52.0%)

Educational bulletins	8 (32.0%)
Scientific literature	7 (28.0%)
Health campaigns	3 (12.0%)
Other	0 (0.0%)
Does not know	0 (0.0%)
Does not answer	0 (0.0%)

4. Discussion

This is the first study conducted to identify Pan-American notable people with HNC and assess the perspective of health professionals with experience in HNC concerning communicating stories of notable patients with HNC to promote prevention.

Notable people from different fields and have the potential to influence a large number of lay people. [13] A cross-database of notable people grouped into occupational domains showed that the four most popular are, in decreasing order: culture (30.6%), sports/games (27.7%), leadership (27.0%), and discovery/science (11.9%). [14] The above results are a plausible explanation for why our study among 42 notable people identifies actors, athletes, and musicians were the most reported profession. Regardless of their occupation, when a notable person becomes affected by a disease the public interest in the health issue may arise. [12] A study identified a positive correlation between high periods of internet searches for the most common types of cancer (e.g. breast, lung, cervix) in the world and the advertisement of notable people diagnosed with the particular cancer reported in the media. [16] There was evidence to suggest that notable people's HNC diagnoses may promote primary prevention. For example, in 2011, the laryngeal cancer of Brazilian President Lula da Silva was attributed to smoking and his case led Brazilian policymakers to increase the already existing aggressive tobacco control agenda. [17] Moreover, there was a significant increase in smoking cessation consultations compared to the week of Brazil's National No Tobacco Day or World No Tobacco Day during the entire 4-week period following the announcement of Brazilian president Lula's cancer. [17]

Prevention strategies for HNC involve a decrease in exposure to risk factors (e.g. tobacco, and alcohol consumption) and implementing HPV vaccination in primary prevention of HPV related cancers. [6,18] Early detection for oral cancer may be possible through screening due to being easily accessible to visual inspection. [19,20] In our study, participants demonstrated a positive outlook regarding the potential of sharing reported stories of notable individuals diagnosed with HNC to promote primary prevention by reducing risky behaviors and encouraging early detection. The participants highlighted the effectiveness of using various communication channels, including the web, followed by social media and television. With the widespread adoption of internet usage among the general population, it has emerged as a significant source of health-related information. [21] Also, it is known that news about notable people are shared more frequently [13] and success in social media and communications depends upon sharing activity that causes desirable health messages to rise to the top of people's online social feeds. [22]

The data presented in this study represents an important initiative aimed at promoting the use of notable individuals' stories as a prevention strategy for HNC. The study successfully identified cases of notable individuals with HNC that were covered by the media or reported in the literature, shedding light on the positive perspective of professionals regarding the potential role of these individuals in prevention efforts. However, it is important to acknowledge that the study's limitation lies in the relatively small number of participants who responded to the survey, as they were solely from Pan-American countries.

This is a hypothesis-generating study that might encourage professionals to motivate notable people with HNC diagnoses to talk openly about their disease based on reliable scientific information. Also, future studies could focus on surveillance and measure the impact (e.g., quality of information, circulation time, number of citations in social media, and internet search) of increasing public awareness following the transmission of stories of notable people with HNC.

5. Conclusions

Prominent figures from various fields who have experienced HNC can serve as excellent advocates for raising cancer awareness and promoting prevention strategies in the Pan-American region. In this study, a total of 42 noteworthy individuals from eight Pan-American countries were identified. The professionals involved in the study expressed a positive inclination towards using the stories of these notable HNC survivors as an effective prevention strategy.

Supplementary Materials: The following supporting information can be downloaded at: www.mdpi.com/xxx/s1, **Supplementary Table 1:** Search strategies in the databases and grey literature, **Supplementary References 1.** The list of publications reporting Pan-American notable people, **Supplementary Table 2.** Results from survey responses (n = 24) regarding head and neck cancer characteristics of the Pan-American notable people, **Supplementary Table 3.** Pan-American notable people diagnosed with head and neck cancer collected from the structured literature review, **Supplementary Table 4.** List of professionals.

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