Global Oral Cancer Forum – Group 6

Empowering the Public to Drive Policy Development: Role of Media, Government and Non-Profit Organizations

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Oral cancers (ICD-10:C00-C08) are malignant neoplasms that affect the structures and tissues of the mouth [1]. It is one of the most common cancers of the world with over 300,000 new cases and 145,000 deaths annually [2]. It is one of the most common cancers of the world with over 300,000 new cases and 145,000 deaths annually. [2]. This cancer affects both the developed and developing countries, being more common in South Asia, Eastern Europe, Pacific islands and Latin America [3]. The main etiological factors leading to oral cancer are tobacco, areca nut and alcohol [2,3].HPV is one of the established factors for oropharyngeal cancers but no consideration of the increasing trend or impact of HPV are a component of this document.The morbidity and mortality associated with this disease can be reduced by abstaining from tobacco and alcohol use (primary prevention), regular screening of high risk individuals (secondary prevention) and regular follow up of the survivors to for early detection of second primary tumors (tertiary prevention)[4,5].

Influencing changes to improve the mortality and morbidity of oral cancer requires multi-faceted cancer control plans which are associated with significant expenditures. In most cases, the power for meaningful change can only come through governmental intervention. The objective of our group is to summarize the ways in which governments can control oral cancer, and to explore of how media, non-profit organizations, professional societies, and other non-governmental organizations can help drive policy development. Selected programs will be discussed that reveal the power of public awareness to harness change.

Role of Government

The government has an important role in the control of oral cancer by making effective policies around 4 different areas across the cancer continuum: primary prevention, secondary prevention (early detection), treatment and palliative care. In terms of primary prevention, governments can develop policies (and better enforce existing policies) to restrict the demand and supply of the products responsible for oral cancer [6,7,8,9]. The government should involve all the stakeholders of all related sectors in the policy making process to enable commitment and active participation of key players [6]. The decision making should be based on social values and evidence with efficient use of the resources that benefit the target population [6]. One additional major aspect of government cancer control plans is the design and implementation of research programmes. Such programmes are expensive to run, and many developing countries do not have robust cancer research portfolios. Tobacco control is one of the most extensively researched best practices that has led to a drop in oral cancer incidence in many parts of the world [9]. Traditionally, tobacco control has involved creating public awareness and promoting cessation. The WHO Framework Convention on Tobacco Control (FCTC) has been very effective in guiding the countries to formulate and implement the anti-tobacco policies [4]. However, the sustained decline is also the result of effective policies such as - prohibition of smoking in public places, restriction of the sale of tobacco to minors, restriction of direct or indirect advertising and, most importantly, the increase in taxes on tobacco [9]. Every 10% increase in taxes decreases the consumption of tobacco in high and low/medium income countries by 4% and 8% respectively [7]. This approach has been successfully applied in South Africa where there has been a decrease in cigarette consumption across all age and ethnic groups while increasing government revenue [11].

In India, the government has enforced stricter laws under the Cigarettes and Other Tobacco Products Act (COTPA), the Prevention of Food Adulteration Act (PFA), and the Cable and Television Networks Act [12]. Gutka a mixture of areca nut, tobacco and various other flavouring agents has been banned throughout India. The advertisement of tobacco products has been banned in all forms of media, and now governments are using media to educate their populace about the health consequences of tobacco and the benefits of quitting (see Media section below). The punishment on the sale of tobacco products to minors, through the new

Juvinile Justice act, has become harsher with offenders sentenced to seven years imprisonment and a fine of $1500 [12,13]. Australia and New Zealand have reported a sharp decline in tobacco consumption due to very comprehensive tobacco control policy. [14]. Australia became the first nation to introduce plain cigarette packaging[15]. The US Government has provided better access to cessation services resulting in an increase in the use of nicotine replacement therapies (NRT) by more than 150% [14].

Alcohol use is causally linked to oral cancer. Measures similar to those employed for tobacco control have been used for alcohol and several countries have completely banned advertising, marketing and sponsorship by alcohol companies [16]. As of now, 66 countries have framed policies for alcohol control. A majority of the countries have a licensing system for the production of alcohol and many have a monopoly system where the government regulates both its production and sale [16]. Out of the 159 countries whose data was monitored in the global alcohol status report of 2014, 51.3% countries had some form of restrictions on alcohol marketing in media while 10.1% have banned it completely [16].

Areca nut use is an important cause of oral cancer and potentially malignant disorders (OPMDs) in the Indian sub-continent, South-East Asia, Taiwan and certain pacific islands. In addition to the gutka ban throughout India, pan masala, a flavoured areca nut product which does not contain tobacco has been banned in many states of India under the Food Safety and Standards Act [12]. USA has imposed an import alert on areca nut and UAE (United Arab Emirates) has banned it completely [17, 18]. The International Agency for Research on Cancer declared betel quid as a carcinogen for oral cancer [19].

In terms of secondary prevention (ie early detection), governments can develop national screening programmes, and evidence for such programmes has been covered by Group 3.

Governments need to define priorities of public health and need to provide affordable and equitable treatments across all regions [20]. Government assistance is required to develop both standardized curricula and guidelines for cancer treatment, customized according to the available resources and health insurance policies [20]. Furthermore, all governments must develop oral cancer prevention strategies in their countries, particularly for high risk patients.

Secondary Prevention and Chemoprevention

Primary care health workers, general practitioners and dentists play an important role in secondary prevention. . High risk individuals who have history of tobacco, alcohol and areca nut use are recommended to perform a regular Mouth Self Examination (MSE) in front of mirror with good illumination to inspect and palpate for any suspicious white or red patches, ulcers or swellings and report to physicians/dentists if any abnormalities are appreciated [21].A spectrum of diagnostic modalities are available for early diagnosis of oral cancer, ranging from the traditional methods like Lugol`s iodine, toludiene blue to the latest methods using DNA-analysis, Laser capture microdissection [22]. The delay in diagnosis leads to progression of disease and loss of precious time as early discovery and diagnosis leads to a significant reduction in treatment related morbidity and the possibility of improved long term outcomes. [23, 24]. . Chemoprevention involves the use of synthetic drugs or natural products that can reverse or arrest malignant transformation of oral pre-malignant lesions (OPML) to address the changes related to field cancerization [25].Various natural products which have been tried as chemopreventive agents but they are mainly used in trial setting due lack of large randomized control trials and inconsistent results.

Role of Media

Mass media is one of the most powerful medium for communication in the world today by the means of newspapers, TV, radio, magazines, internet, mobile phone applications, text messages and gaming [9]. Mass media campaigns are among the most effective ways to make people aware about the hazards of tobacco/alcohol/areca nut use and to encourage the users to quit. It also creates support for implementation of policies [9]. For years, the tobacco and alcohol industries used this medium to their advantage by presenting their products as attractive and socially-desirable [9]. Now governments and advocates are using media to reverse those perceptions and educate the people about its harmful effects and eventually quit [27]. Using all forms of media (TV, print and social media), mass campaigns now use graphic images and emotional messages to present the health effects of tobacco use [9]. Such advertisements shatter are very effective in making the smokers realise the harm of tobacco use. The recent examples of such campaigns include the Sunita campaign in India [27] where a young female cancer survivor illustrates her emotional battle with cancer due to tobacco use, and the Idrissa testimonial campaign from West Africa [27]. The “Smoking Kid” campaign from Thailand show children approaching the adult smokers for a cigarette, and the adults refused and reminded them about

the hazards of smoking. This emotional campaign led to a 40% increase in calls to the national quit line and over 5 million YouTube views within 10 days [27]. The 2001 National Tobacco Campaign (NTC) in Australia increased frequency of negative thoughts about smoking, cessation related activity [28]. The 2013 *Tips* campaign in USA showed the regions receiving higher exposure of anti-tobacco ads had a higher recall rate as compared to regions receiving the standard exposure.. The relative quit attempt rate was 11% higher in higher-dose markets compared to standard-dose markets (38.8% Vs 34.9%; $p<0.04$). In addition, non-smokers in higher dose markets were more likely to talk with family or friends about the dangers of smoking (43.1% Vs 35.7%; $p<0.01$), and had greater knowledge of smoking-related diseases [29].The Mukesh Harne campaign featuring the story of a 24 year old boy from Maharashtra was produced at the Tata Memorial Hospital, Mumbai, where Mukesh was admitted for treatment. The ad campaign was launched on television and radio in January 2011and emphasised how the tobacco chewing addiction of this Indian youth lead to his painful death, leaving his family in misery The campaign had a far-reaching effect on tobacco users all over India and many youngsters quit tobacco after watching it [30]. Wakefield et al showed that each 1000 GRP increase per quarter led to 11% increase in making a quit attempt [odds ratio (OR) 1.11, 95% confidence interval (CI) 1.03–1.19, P <0.009] which were unrelated to NRT advertising. The anti-tobacco advertising is associated with short-term increases in smokers making a quit attempt. Repeated cycles of higher intensity anti-tobacco media campaigns were needed to sustain increased levels of quit attempts [31].

Numerous studies have consistently shown that exposure to media and the marketing activities of alcohol companies is associated with the likelihood that adolescents will start to drink and will further increase the habit amongst current users [32]. Sargent et al showed that after 11 hours of exposure to movies showing alcohol use there was a 20% increased incidence of alcohol use in adolescents [32]. Snyder et al in a study on 15-26 year age group showed that for every dollar per capita spent on advertisements the money spent on alcohol increased by 3% and exposure to every additional advertisement increased the number of drinks by 1% [32].

Effect of Celebrity Endorsements

Celebrities have been employed since the first half of the last century to advertise tobacco

products [33].By the late 1940's and early 1950's, TV and print advertising commonly featured athletes and movie stars describing the pleasures of smoking cigarettes and cigars.[33]. In the latter half of the 20th century when the harmful effects of smoking became evident the companies used the celebrities to promote smokeless products which were falsely propagated as being safer than smoking [29]. These were associated with car racing and rodeo events and led to increased use amongst the youth [29]. In 1996, Australian cricketer Shane Warne was allegedly paid $123,000 to advertise his efforts to stop smoking [34]. The public health community was delighted that the massive popularity of Warne drew attention to the smoking cessation and led to an enormous increase in the sale of NRT. This clearly demonstrated a causal relationship between quit attempts and celebrity endorsements [34]. Alcohol companies are increasingly partnering with popular actors and sportspersons to promote their brands and even offer stakes in their companies. Notable ambassadors of alcohol brands are George Clooney, Angelina Jolie and David Beckham [35]. Michael Douglas the popular movie actor was diagnosed with oropharyngeal cancer, this event garnered lot of media attention and made the people aware aboutthis disease and the etiological factors [36].

Celebrities have been used in anti-tobacco campaigns since 1960`s, notable amongst them are skater Peggy Fleming, actors John Cleese and Brooke Shields [37].

Oral Cancer Campaigns

Various oral cancer awareness campaigns throughout the world have helped people realise the dangers of tobacco and alcohol and also made them aware about this disease. The West of Scotland awareness program was a multicomponent cancer detection program where the at risk population was encouraged to present to the National Health Service (NHS) early if experiencing signs and symptoms of oral cancer. It involved the training of medical professionals, improved referral pathway and priority to high risk cases. It helped the people living in remote areas and also detection of cases in early stages [38]. An oral cancer campaign by the American Dental Association in 2001 induced positive behavioural changes amongst the dentists and consumers. It made the dentists more vigilant to detect the early lesions and also helped them educate their patients about the signs and symptoms of oral cancer [39]. A case control study comprising house to house survey was done in three parts of rural India involving 36,471 tobacco users. The individuals were interviewed about their tobacco habits, examined for pre-cancerous lesions and

given personal advice to give up their tobacco habits. In 2 out of 3 areas substantially more people decreased the frequency of use and gave up their tobacco habit as compared to the control group while the remaining third area showed slightly higher proportion of people quitting this habit with no difference in reduction of frequency of use. The incidence rate of leukoplakia decreased substantially in all the areas [40].

Effect of Non-Profit Organizations

Non-profit organizations (NPO) play an integral and vital role in cancer control. They can bolster awareness about cancer and effects of tobacco and alcohol though media campaigns, provide vital financing for research on cancer, lobby governments to generate policies involving alcohol, tobacco use and allocation of more funds towards cancer. A number of different organizations are working throughout the world in an attempt to tackle the issues concerning oral cancer.

Oral cancer**:** There are numerous NPOs working to prevent oral cancer in various parts of the world.

The *Oral Cancer Foundation* (www.oral cancer.org) is a US based national public service, non-profit entity designed to save lives through research, education, prevention, advocacy, and patient support activities. Some of its ongoing campaigns include oral cancer awareness month, "I'm the part of the Change", etc [41]. It partners with all the major US dental professional societies) to conduct free screenings in their offices during that month of April. A 16 year long effort, it has provided over65k free screenings in that one month (2015) with thousands of dental partners

Oral Head and Neck Cancer Awareness (OHANCA) (www.headandneck.org/get-involved/ohancaw)*:* It is a cancer awareness program that organizes free screenings all over the world and supports head and neck cancer patients throughout the year [42].This year OHANCA week is scheduled for April 10-16, 2016 [42].

Make sense campaign (www.makesensecampaign.eu/): it was designed by the European Head and Neck Society (EHNS) to raise awareness of head and neck cancer to improve the survival outcomes among patients. Its main aim was to educate the general public on disease prevention,

screening and proper treatment [43].

The Ben Walton Trust(www.benwaltontrust.org): Formed in 1996, this trust is very active in action against oral cancer in young. The trust activities include training of the Dentists and GPs to indentify the oral cancer in the early stages. It forms action groups and uses every available official network, dental and medical groups, local and national organizations that have an interest in this disease, and patient support groups and charities. They set up and repeat annually, oral cancer awareness week/months. Funds raised in this way go into research, patient support and awareness events.
One of their most successful projects has been working with BMJ Learning on Mouth cancer: recognizing it and referring early. It has international uptake, designed for Medical professionals it has also been widely used by the Dental profession. The message from the trust is "Almost anyone, of either sex, young or old, smoker and non smoker, drinker or abstainer can be at risk for mouth cancer."In the younger age group, traditional risk factors can be absent, calling for an open mind and vigilance [44].

World Head and Neck Cancer Day (www.ifhnos.org/world-cancer-day): To draw the world's attention on effective care and control of head and neck squamous cell cancer(HNSCC), the International Federation of Head and Neck Oncology Societies (IFHNOS) declared 27th July as World Head & Neck Cancer Day (WHNCD) on the occasion of its 5th World Congress in New York on 27th July 2014. Numerous programs were organized in the participating countries on this day to make the people aware about this disease and also about the etiological factors [45].

Mouth cancer Awareness (Action) Programs (UK, Ireland)(www.cancer.ie). Both countries have a week or month set out for awareness campaigns and action. MCAW-UK is launched at the House of Commons every year and runs for a month. In Ireland for a week and get volunteer dentists to do screening during the week [46].

Tobacco: The anti-tobacco campaigns have support of numerous NPOs around the world to make the people aware about its hazards.
World Lung Foundation (www.worldlungfoundation.org): The organization focuses on tobacco control and believes that mass media campaigns are an effective tobacco control strategy. It has supported various campaigns all over the world notably the smoking kids campaign, sponge

campaign and the Sunita campaign [47].

Voice of Tobacco Victims (VOTV) (www.vovindia.org): Voice of Tobacco Victims (VOTV) is a non-profit organization working in India comprising cancer survivors and motivated oncologist all over the country [48]. This campaign has played the chief role in the pan-India gutka ban, increased taxes on tobacco products and decline in volume sale of chewable tobacco and cigarettes by 26% and 3% respectively [48].

Campaign for Tobacco Free Kids (CTFK) (www.tobaccofreekids.org): It is one of the leading NPOs working all over the world to reduce tobacco use. It works to save lives by advocating for public policies that prevent kids from smoking, help smokers quit and protect everyone from secondhand smoke [49].

Alcohol: The anti-alcohol campaign is being supported by various NPOs internationally.

Alcoholics Anonymous (www.aa.org): Working in many parts of USA, Europe and Asia it brings together people who help each other to solve their common problem related to alcoholism [50].

Summary

Oral cancer is a disease that is common, deadly, and preventable. If not prevented, it can be diagnosed early with effective, simple, and inexpensive treatments that have limited morbidity. When diagnosed late, those afflicted with this disease and their families realize the effect on talking, eating, chewing, drinking, kissing and sometime major cosmetic deformities from the cancer and its treatment. It is often stated that no other cancer has a more profound impact on quality of life than oral cancer. Now is the time that governments, medical and dental organizations, non-profits must work together to institute well-described effective national and international strategies to reduce the incidence and morbidity from this disease through primary and secondary prevention.

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