

KNOWLEDGE OF HEAD AND NECK CANCER AND SMOKING BEHAVIOR IN A HIGH-RISK POPULATION IN INDONESIA

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Abstract. The study assessed knowledge, perceptions, and attitudes toward head and neck cancer in Indonesia, a country with the highest male smoking prevalence in the world. A survey was administered to Indonesian men ($n = 98$) who were either current or former smokers, at a waiting room of a university hospital in Makassar, South Sulawesi to assess knowledge of head and neck cancer. Ages ranged from 21-73 years and education level ranged from no education to doctorate degree. Knowledge scores ranged from 0-71% correct (median = 29% correct). There were no statistical differences in knowledge scores among men of different ages, religious affiliations, education levels, or smoking status, but participants who perceived cancer risk from smoking had significantly higher scores ($p \leq 0.01$). There was no significant difference in knowledge scores between patients with and without head and neck cancer. Only 37% of participants believed they were at risk for developing head and neck cancer, even though 82% correctly identified smoking as a risk factor. All participants reported that they would seek medical treatment if diagnosed with head and neck cancer and 73% reported they would consider quitting smoking following a positive screening. In conclusion, the study highlights the need for increased public head and neck cancer awareness, education of health care providers, community screenings, and tobacco cessation programs targeting high-risk populations.

Keywords: cancer awareness, head and neck cancer, Indonesian male adult, smoking

INTRODUCTION

Head and neck cancer (HNC), which includes cancers of the oral cavity, salivary glands, nasal cavity, paranasal sinuses, pharynx, and larynx, is the most common cancer in many low-income countries, but is comparatively less common in

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higher-income nations, such as the United States of America (USA) where HNC is the 8th most common cancer by incidence (Siegel *et al*, 2019). Tobacco smoking represents the greatest risk factor for HNC, followed by alcohol, sunlight exposure, and human papillomavirus infection (Marur and Forastiere, 2008). Smoking is estimated to account for nearly 75% of all HNC cases in the USA (Luryi *et al*, 2014), where the prevalence of tobacco use for men and women is 17% and 13%, respectively, and the HNC incidence rate is four times higher in men than in women (WHO, 2020). Indonesia, the fourth most populous nation in the world and classified as a lower middle-income country, has the highest male smoking prevalence, with nearly 63% of Indonesian men over the age of 15 years consuming cigarettes and tobacco (WHO, 2019). It is not unexpected that HNC is the most common cancer affecting Indonesian males, accounting for 8.7% of all new cancer cases each year and with over 30% of the total Indonesian population estimated to be at risk for HNC (WHO, 2020).

Many low- and middle-income countries such as Indonesia continue to experience a high proportion of HNC compared to other cancers and this health burden is compounded by the limited availability of resources used to diagnose, treat, and prevent HNC, including medical personnel and treatment facilities (*eg* radiotherapy centers) (Joshi *et al*, 2014). A major contributor is the delay in diagnosis of HNC, leading to disease progression. Low awareness of HNC signs and symptoms is a consequential concern as it has been shown to impact patients' healthcare seeking behavior and to result in presentation at late, incurable stages of the disease (Austoker

et al, 2009). When diagnosed in the early stages, however, HNC is among the most treatable cancers, with surgical resection, radiotherapy and chemotherapy serving as effective modalities in most cases (Rettig and D'Souza, 2015). Due to the lack of screening guidelines in many countries including the USA, prevention of HNC depends primarily on patients' self-recognition of signs and symptoms.

Several studies have been conducted in the USA to gauge the public's general awareness and knowledge of HNC. An earlier study showed that self-reported knowledge of HNC was very low among a random sample of US adults surveyed online, with only 33% of respondents considering themselves knowledgeable about HNC (Luryi *et al*, 2014). Another study conducted in a high-risk Native American population demonstrated low overall HNC knowledge (mean knowledge score = 59%) and significant under-utilization of community screenings for HNC (Dwojak *et al*, 2015). There is limited documentation on knowledge of HNC in low- and middle-income countries to date, especially among high-risk populations (Joshi *et al*, 2014). Earlier studies in Indonesia focused primarily on two subtypes of HNC and assessed awareness among the general and elderly populations (Wimardhani *et al*, 2018; Wimardhani *et al*, 2019) and among medical practitioners (Fles *et al*, 2010).

Here, knowledge and perceptions of HNC in a high-risk Indonesian population were assessed, with the hypothesis that there would be significant differences in knowledge levels, perceptions, and attitudes between current and former Indonesian male smokers, as well as between HNC patients and participants not diagnosed with the disease. These findings should be of assistance in

enabling behavioral change, namely smoking cessation following a diagnosis of HNC.

MATERIALS AND METHODS

Study site and participants

The study was conducted in Makassar, South Sulawesi, Indonesia, owing to its large size (population 1.7 million) and socioeconomic diversity, providing a highly representative sample of the Indonesian male smoker population.

Study participants were recruited through convenience sampling at an outpatient waiting area of the Hasanuddin University Hospital (R.S. UNHAS) and the survey was administered between November and December 2018. The target sample size was based on a previous study ($n = 100$) that focused on differences in oral cancer knowledge levels among education levels in Indonesia (Wimardhani *et al*, 2018). Since our target population was more vulnerable than the population examined by Wimardhani *et al* (2018), an equivalent sample size ($n = 100$) was chosen. However, two of our participants were excluded because of insufficient survey responses, and due to limited resources and logistical challenges in the hospital setting, we were unable to recruit additional participants to make up for the loss. Thus, a total of 98 Indonesian men, both current and former smokers, completed the survey. Although non-smokers were excluded from the study, very few were encountered during the survey period. The decision to exclude female participants was based on our study objective of examining the larger, high-risk male population (*eg* tobacco smokers >15 years of age).

The study protocol was approved by the Northern Illinois University

Institutional Review Board (IRB #HS16-0174: Community and Occupational Health Associated with Sustainable Development Goals), the Ethics Committees of Hasanuddin University (7769/UN4.26.1.2/PL.00.00/2018), and the City of Makassar (070/0900/DP/XI/2018 and 8137/S/01PTSP/2018). Prior written and verbal consent was obtained from each adult participant and parents or legal guardians of those below the legal age of consent.

Data collection

The study was modeled on the "About Face Survey", a validated instrument developed by the European Head and Neck Society to assess HNC knowledge of anatomical sites, risk factors and symptoms in European populations (Leemans *et al*, 2009) and later in a US Native American population (Dwojak *et al*, 2015); however, the survey has never been used in low- and middle-income countries. Additional questions on health behaviors and demographics specific to the Indonesian community were added and the questionnaire was translated to Bahasa Indonesian language. After a pilot test of the questionnaire among a group of 10 volunteer hospital staff and visitors to assess survey feasibility, a trained research team administered the questionnaire, which was comprised of 64 questions on demographic characteristics, knowledge of HNC and smoking behavior, and took participants approximately 15 minutes to complete.

Statistical analysis

Data collected from the surveys was verified for accuracy prior to recording in Microsoft Excel. Missing values from demographic and behavioral survey questions were excluded. Chi-square and *t*-test was used for categorical and

numerical variables, respectively, to compare differences in outcomes across the various demographic groups. Odds ratio was used to evaluate associations between smoking behavior and demographic characteristics as well as related outcomes including knowledge scores and attitudes. Logistic regression was used to rule out possible confounders, such as smoking status and age. A p -value ≤ 0.05 was considered significant. All analyses were performed using IBM Statistical Package for the Social Sciences (SPSS) version 25 (IBM, Armonk, NY) and SAS 9.4 (SAS Institute Inc, Cary, NC).

RESULTS

Demographic profile of Indonesian male participants

The age of respondents ($n = 98$) ranged from 21 to 73 years with 52% identifying as current smokers. A majority (79%) of the participants were married. The participants' religious affiliations (88% Islam and 12% Christianity) were consistent with the national statistics regarding religion demographics in Indonesia (Central Intelligence Agency, 2020). The median education level was diploma degree, which is 1-3 years beyond the compulsory high school education in Indonesia.

There were no statistical differences in marital status, religious affiliations, education level, or mean (\pm SD) number of years smoking (18 ± 10 years) between current and former smokers. The average number of children (2 ± 1) in families of current smokers was significantly lower than in those (3 ± 1) of former smokers ($p \leq 0.01$).

Knowledge of HNC among participants

Only 39% of participants knew the term "head and neck cancer" prior to

taking the survey and 13% personally knew someone diagnosed with HNC. There was no statistically significant difference between the number of current and former smokers who had heard of HNC nor among participants of different ages, religious affiliations, or education levels. Eight (8%) participants (seven former smokers and one current smoker) were HNC patients and all had received treatment.

Correct responses to questions on HNC knowledge ranged from 0 (= 0% correct) to 29 (= 71% correct) out of 41 total questions (one mark per correct answer), with a median score of 12 (= 29% correct) (Table 2). Overall knowledge scores of participants who had prior knowledge of HNC ($36 \pm 15\%$ correct) was significantly higher than of those with no prior knowledge ($29 \pm 21\%$ correct) ($p = 0.04$). There were no significant differences in scores among participants of different ages, religious affiliations, education levels, smoking status, or HNC diagnosis.

Most participants correctly identified the throat (73%) and larynx (59%) as true anatomical sites of HNC, although the overall accuracy of responses to items in the 10-item anatomy section was poor ($33 \pm 24\%$ correct) (Table 2). Only 37% of the participants correctly identified the nose as a true HNC anatomical site, but former smokers were approximately four times more likely to respond correctly than current smokers when controlling for age (Table 3). Approximately 93% of participants incorrectly identified the esophagus and 98% incorrectly identified the brain as HNC sites.

Participants' knowledge of the various risk factors associated with HNC was also poor ($34 \pm 23\%$ correct); however, 82% did recognize tobacco and 67% recognized alcohol drinking as true risk

Table 1
Demographic profile of participants recruited at Hasanuddin University Hospital, Makassar, South Sulawesi, Indonesia
(November – December 2018).

Characteristic	Number (%) (n = 98)	Smoking Status		p-value*
		Current smoker (n = 51) Number (%)	Former smoker (n = 47) Number (%)	
Age				≤0.01
>40 years of age	57 (58)	18 (35)	39 (83)	
Marital status				0.07
Married	78 (80)	37 (73)	41 (87)	
Single	20 (20)	14 (27)	6 (13)	
Religious affiliation				0.28
Islam	86 (88)	43 (84)	43 (91)	
Christianity	12 (12)	08 (16)	4 (8)	
Highest education completed				0.14
No education	3 (3)	2 (4)	1 (2)	
Elementary school (Grades 1-5)	8 (8)	2 (4)	6 (13)	
Secondary school (Grades 6-8)	7 (7)	5 (10)	2 (4)	
High school (Grades 9-12)	29 (30)	14 (27)	15 (32)	
Diploma degree (1-3 years beyond Grade 12)	10 (10)	7 (14)	3 (6)	
Bachelor's degree	37 (38)	21 (41)	16 (34)	
Master's degree and higher	4 (4)	0 (0)	4 (9)	

*Significant at $p \leq 0.05$

Table 2
Knowledge of head and neck cancer (HNC) among participants ($n = 98$) recruited at Hasanuddin University Hospital, Makassar, South Sulawesi, Indonesia (November - December 2018).

When the correct answer is "True"	Number of participants who answered correctly (%)	When the correct answer is "False"	Number of participants who answered correctly (%)
HNC anatomical sites			
Throat [T]	71 (72)	Eyes [F]	16 (16)
Larynx [T]	58 (59)	Ears [F]	16 (16)
Tongue [T]	42 (43)	Esophagus [F]	7 (7)
Mouth [T]	40 (4)	Brain [F]	2 (2)
Nose [T]	36 (37)		
Lips [T]	35 (36)		
HNC risk factors			
Smoking [T]	80 (82)	Kissing [F]	33 (34)
Drinking alcohol [T]	66 (67)	Spicy food [F]	33 (34)
Age >40 years old [T]	42 (43)	Wearing makeup [F]	30 (31)
Male gender [T]	36 (37)	Fatty food [F]	27 (28)
Sun exposure [T]	11 (11)	Frequent colds [F]	24 (24)
Multiple sexual partners [T]	0 (0)	Mouth sore [F]	22 (22)
HNC signs and symptoms			
Lump in neck [T]	75 (76)	Toothache [F]	20 (20)
Sore throat [T]	53 (54)	Lack of saliva [F]	17 (17)
Pain when swallowing [T]	48 (49)	Dry eyes [F]	17 (17)
Pain in jaw or face [T]	45 (46)	Dry skin [F]	17 (17)
Hoarseness or change in voice [T]	38 (39)	Hair loss [F]	6 (6)
Jaw swelling [T]	33 (34)		
Difficulty in chewing [T]	26 (26)		
Persistent nasal stuffiness [T]	24 (24)		
Unpleasant taste in mouth [T]	22 (22)		
Bleeding from mouth [T]	21 (21)		
Bleeding from nose [T]	21 (21)		
Red and white patches in mouth [T]	15 (15)		
Skin change [T]	13 (13)		
Earache [T]	13 (13)		

F: false; T: true.

factors for HNC (Table 2). Although only 37% of the participants correctly identified their male gender as a risk factor for HNC, current smokers were approximately three times more likely to be aware of

their gender as a risk factor compared to former smokers (Table 3). Two-thirds of participants incorrectly believed such behaviors as kissing and eating spicy and fatty foods are risk factors for HNC.

Only 11% of respondents were aware that sun exposure is a risk factor, and no respondents were aware that having multiple sexual partners was a risk factor for HNC.

Participants' knowledge of signs and symptoms of HNC was the lowest among the three quiz sections ($28 \pm 25\%$ correct) (Table 2). While 77% and 54% of the respondents correctly identified lump in the neck and sore throat as signs and symptoms, respectively, only 20-49% of participants correctly identified other signs and symptoms of HNC, such as pain with swallowing, jaw and facial pain, hoarseness or change in voice, swelling of jaw, and difficulty in chewing. Current smokers were approximately three times more likely than former smokers to recognize lump in the neck as a sign of HNC (Table 3). On the other hand, former smokers were approximately 3-11 times more likely than current smokers to identify jaw swelling, bleeding from the nose, difficulty chewing, and earache as true signs and symptoms of HNC (Table 3). Additionally, only 13-15% of participants correctly identified red and white patches in the mouth, skin changes, and earache as true signs and symptoms of HNC.

Perceptions and attitudes toward HNC

Only 37% of the participants believed they were at risk for developing HNC, despite 82% correctly identifying smoking as a risk factor for HNC (Table 2). There was no statistically significant difference in this perception between current and former smokers, nor between HNC patients and those not diagnosed with HNC. Participants who were married were approximately four times more likely to feel at risk for HNC compared to single participants (Table 3). Less than half of participants recognized age over

40 years as a risk factor, but participants >40 years of age were approximately three times more likely to be aware of their increased risk for developing HNC compared to younger participants (Table 3). Although overall knowledge scores were low, participants who felt that they were at risk for HNC achieved significantly higher scores than those who did not feel at risk ($p \leq 0.01$).

All participants responded in the affirmative when asked whether they would seek treatment if diagnosed with HNC, with 88% believing that HNC was curable (Table 2). There was no statistically significant difference regarding this issue between current and former smokers, nor between HNC patients and other participants. Seventy-three percent of participants who had not been diagnosed with HNC responded they would consider quitting smoking if diagnosed, while the remaining respondents were unsure if they would do so.

DISCUSSION

This is the first study to assess head and neck cancer awareness in Indonesian male current and former smokers and to document low knowledge levels of HNC anatomic sites, risk factors, and signs and symptoms in this high-risk population. Despite our study population being at higher risk for HNC, the findings are consistent with earlier studies reporting low HNC knowledge in non-Indonesian populations (Dwojak *et al*, 2015; Luryi *et al*, 2014). Study participants were most deficient in knowledge of signs and symptoms of HNC, which poses serious health concerns from the standpoint of measures on HNC prevention, early diagnosis, and recognition of disease. There is strong evidence that patients

Table 3

Adjusted odds ratio for survey questions on head and neck cancer (HNC) given to participants recruited at Hasanuddin University Hospital, Makassar, South Sulawesi, Indonesia (November - December 2018).

Variable	Adjusted OR (95% CI)	p-value*
Knowledge		
Lump in neck as HNC sign		
Current smoker	3.39 (1.04-11.10)	0.04
>40 years of age	0.25 (0.06-1.01)	0.051
Earache as HNC symptom		
Former smoker	11.2 (1.27-99.0)	0.03
>40 years of age	0.61 (0.16-2.39)	0.48
Bleeding from nose as HNC sign		
Former smoker	3.26 (0.99-10.6)	0.051
>40 years of age	1.18 (0.35-3.95)	0.79
Difficulty chewing as HNC symptom		
Former smoker	3.29 (1.10-9.80)	0.03
>40 years of age	1.82 (0.57-5.75)	0.31
Jaw swelling as HNC sign		
Former smoker	2.93 (1.08-7.94)	0.03
>40 years of age	1.97 (0.69-5.62)	0.21
Nose as HNC anatomical site		
Former smoker	4.02 (1.49-10.9)	≤0.01
Self-awareness		
Risk of HNC		
Married	3.75 (1.00-14.0)	0.05
Current smoker	0.59 (0.25-1.40)	0.23
>40 years of age as HNC risk factor		
>40 years of age	3.49 (1.30-9.36)	0.01
Current smoker	0.76 (0.30-1.96)	0.57
Male gender as HNC risk factor		
Current smoker	2.77 (1.04-7.35)	0.04
>40 years of age	1.15 (0.45-1.02)	0.78

*Significant at $p \leq 0.05$; OR: odds ratio; CI: confidence interval.

who lack awareness of the cardinal signs and symptoms of HNC may fail to seek medical attention at the early, treatable stages of the disease (Austoker *et al*, 2009). For early-stage (Stage I or II) HNC, the 5-year survival rate is nearly 90%, but falls to less than 30% for advanced-stage

disease (Stage III or IV) (Datema *et al*, 2010). Although our study sample size was small, the finding that HNC patients did not demonstrate greater knowledge of their condition than participants not diagnosed with HNC is worrisome and may point to inadequate patient

education and weak emphasis placed on HNC prevention by medical providers. A shift in focus to prevention of HNC will be necessary to promote reduction in disease recurrence and empower patients to spread awareness to others who may be at risk.

It was initially hypothesized that current smokers were not cognizant of the risk of HNC associated with tobacco smoke compared to former smokers; however, the results demonstrated no difference in such awareness between the two groups. Various factors may have contributed to this finding, such as perceptions of tobacco use (*eg* quantity needed to become “at risk”) and/or failure to recognize (or lack of) any current signs or symptoms. This highlights the gap between participants’ knowledge and self-perceptions of smoking, which has negative consequences with regards to increasing HNC risk. Further investigation into the reasons leading to smoking cessation is necessary and may shed light on potential predictive factors, which may also aid in the development of effective interventions. Owing to the low awareness of HNC in both current and former smokers, our results suggest that prevention of HNC was unlikely to be the primary motivator for smoking cessation in our cohort of former smokers.

Our study demonstrated no significant association between age and knowledge of HNC in the Indonesian male participants, unlike a previous study conducted in the USA showing a positive correlation between age and knowledge level as well as a discrepancy between adolescent awareness of HNC and lung cancer risk factors (Nugent and Moore, 2010). As the participants in our study were all older than 20 years, we were unable to evaluate whether younger people have

poorer HNC knowledge compared to older individuals. Future studies should investigate HNC knowledge and perceptions among Indonesia youth as it may provide valuable insight into improving Indonesia’s education and health systems on this public health issue.

The finding that all participants would seek treatment if diagnosed with HNC and that most would consider quitting smoking following a diagnosis adds support for community-based interventions for HNC screening and smoking cessation. Screenings have been reported to not only detect positive clinical findings, but also to promote tobacco cessation in populations with a high smoking prevalence (Hapner *et al*, 2011). In other predominantly Muslim populations such Bangladesh and Pakistan, mosques have demonstrated success as community centers for public health initiatives and focus groups for smoking cessation (King *et al*, 2017). In planning future interventions, Indonesia may also experience success in utilizing such locations to serve as sites for HNC screenings, anti-tobacco education, and counseling. Regarding the benefit of smoking cessation, an earlier study showed reversal of HNC risk to the level of non-smokers following cessation for a minimum duration of 20 years, and a 30% reduction in head and neck cancer risk after 1-4 years of smoking cessation (Hapner *et al*, 2011). Furthermore, there are reports showing improvement in the quality of life for HNC patients who quit smoking following treatment (Jensen *et al*, 2007). When and why former smokers quit smoking was not explored in this study, and future studies should investigate the answers to these questions as well as the efficacy of smoking cessation and quality of life in this specific population.

Future studies should also include female participants to examine potentially important differences in knowledge and perceptions of HNC between the low- and high-risk Indonesian populations. The study demonstrates the need for public health efforts to provide education on HNC to the Indonesian population as well as the means to detect early signs and symptoms of HNC in high-risk patients. Dwojak *et al* (2015) showed that higher level of education predicts greater knowledge of HNC in Native American populations, who are at greater risk of HNC than other communities within the USA, however, such a correlation was not observed in our study population. This may be largely due to health education not being officially mandated in the Indonesian school curriculum. Educational efforts beyond the formal school settings will be required to increase HNC awareness, especially among the youth, in order to further minimize the risk of HNC. In addition to educating the general public, there is also a need for educating primary care providers, whose limited knowledge of HNC may impact early HNC detection and restrict the benefit of patient education alone. Fortunately, efforts to educate medical providers on the signs and symptoms of HNC are already underway to help identify at-risk patients who may need further evaluation (Fles *et al*, 2016). In addition, increased education of dental care providers may prove vital, as dentists and oral hygienists have been shown to play strong roles in the initial detection of HNC and subsequent referral to medical specialists (Golusinska-Kardach *et al*, 2016).

Increase in HNC awareness, early detection, prompt treatment, and tobacco control in Indonesia will require

a systems-thinking approach, which encourages input from stakeholders from the educational, healthcare, religious, and household sectors. Ultimately, both national and international governing bodies can contribute significantly to the reduction in HNC incidence and other tobacco-related illnesses, particularly through ratification of the World Health Organization Framework Convention on Tobacco Control (WHO FCTC) (WHO, 2014). This treaty is the first to enact regulatory strategies to reduce tobacco use worldwide and the findings of our study would directly support the enforcement of specific treaty provisions, including increasing public awareness of the health consequences of smoking, protection from secondary tobacco exposure in public spaces, a comprehensive ban on tobacco advertising, and an increase in tobacco-related health research in Indonesia. Nations with a high smoking prevalence, such as Brazil and India, which have signed WHO FCTC have already experienced reductions in tobacco-related diseases, including cancer and lung disease (WHO, 2014).

There are several limitations to this study including dependence on convenience sampling to recruit participants, thereby preventing generalizability of the results to the male smoker population at large in Makassar. Moreover, the low number of participants recruited further limits the generalizability of our findings and a larger sample size is needed to evaluate the outcomes of patient education and difference in HNC knowledge between HNC patients and other participants. Our survey instrument, which was modeled on a version of questionnaires used in European and Native American head and neck cancer knowledge studies, may not take into

account the cultural and behavioral differences within the Indonesian setting. Additionally, our questionnaire intended to examine general interests in undergoing screening for HNC, but the majority of survey participants did not respond to the question "Are you interested in being screened for head and neck cancer?". This may have resulted from a communication gap between survey developers, administrators and participants. It was believed that the participants misinterpreted the question as offering a screening at the time of the survey and therefore may not have provided a response due to lack of willingness or time to commit to a screening at that moment. Given this was the first time the survey was used in Indonesia, further revisions and validations to adjust for the target populations are required in future studies.

In conclusion, the study highlights the urgent need for increasing head and neck cancer education, community screenings, and continued programs on tobacco cessation in Indonesia. Due to the high prevalence of male smokers and health disparities in Indonesia, the incidence of head and neck cancer is very high in this population; however, it is also among the most treatable cancers if diagnosed and treated early, and smoking represents the strongest, but most modifiable risk factor for the disease. With the full support of local and national governments, healthcare providers, educators, and community leaders, Indonesia should begin to experience a reduction in the incidence of head and neck cancer as well as other causes of tobacco-related mortality.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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