

# Public awareness of central nervous system tumors in the Kingdom of Saudi Arabia

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## ABSTRACT

**الأهداف:** للتحقق من مستوى المعرفة لعلامات أعراض وعوامل الخطر لأورام الجهاز العصبي وتقبل الحاجة لطلب المشورة الطبية.

**الطريقة:** أجريت دراسة مقطعية لعينة من المجتمع باستخدام طريقتين مختلفتين. تم تعبئة 1,500 استمارة شخصية و 1,500 استبيان عبر الإنترنت موازية بين شهري يونيو 2015 و يونيو 2016م لسكان المملكة العربية السعودية.

**النتائج:** لوحظ وجود فروقات كبيرة في الخصائص الاجتماعية الديموغرافية للمشاركين عبر الطريقتين. وكانت أكثر الأعراض التي تم التعرف إليها هي «الصداع» (45.2%) وعامل الخطر الأكثر تمييزاً هو «العمل في أماكن يوجد بها اشعاعات» (84.1%). وكانت درجات المعرفة العامة منخفضة، كما أنه تم ملاحظة ارتباط امكانية توقع ارتفاع مستوى المعرفة مع وجود وظيفة أو علاقة بمرض السرطان ( $p < 0.05$ )، وكانت درجة المعرفة أعلى بكثير في المشاركين الذين كانوا على استعداد لرؤية أطبائهم في غضون أسبوع ( $p < 0.005$ ). وكان العائق الأكبر لطلب المساعدة هو «القلق بشأن ما قد يكتشفه الطبيب» (74.0%).

**الخاتمة:** كان مستوى المعرفة لعلامات أعراض وعوامل الخطر لأورام الجهاز العصبي منخفض. استخدام طريقتين لتوزيع الاستبيانات يمكن أن يساهم في جمع عينات ذات خصائص اجتماعية ديموغرافية مختلفة.

**Objectives:** To investigate individuals' knowledge about central nervous system tumors (CNST) signs and symptoms and risk factors, as well as their readiness to seek medical advice. The signs and symptoms associated with CNSTs are often vague, and failure to recognize them could lead to delays in seeking help and possibly fatal results.

**Methods:** This was a cross-sectional survey that utilized 2 delivery methods. A total of 1,500 personally delivered and 1,500 online self-administered questionnaires were completed in parallel between

June 2015 and June 2016 for the occupants of the Kingdom of Saudi Arabia.

**Results:** Significant differences were observed for the sociodemographic characteristics of participants recruited via the 2 methods. The most recognized symptom was "Headaches" (45.2%), and the most recognized risk factor was "Radioactive location/occupation" (84.1%). Overall knowledge scores were low, significantly predicted by employment and cancer contact ( $p < 0.05$ ), while the scores significantly higher for participants who were willing to see their doctors within a week ( $p < 0.005$ ). The most recognized barrier to seeking help was "Worry about what the doctor might find" (74.0%).

**Conclusion:** The level of awareness of CNSTs was low. Using a questionnaire delivered in 2 different ways enabled the recruitment of sample pools with different sociodemographic characteristics.

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For many health-related issues, awareness is considered an important factor associated with behavior.<sup>1</sup> Several studies have linked high knowledge to the ability to address modifiable associated causes,

for instance, improving diet and increasing exercise to prevent cancer, as well as taking appropriate actions in response to detecting associated symptoms.<sup>2</sup> Assessing the level of public awareness of health-related issues is important for identifying deficient areas and increasing awareness in areas where needed.<sup>3</sup> The occurrence of a central nervous system tumor (CNST) in any individual, with its associated consequences, is a devastating event.<sup>4</sup> In 2012, the World Health Organization (WHO) Global Cancer report (GLOBOCAN) stated that more than 250,000 individuals worldwide were diagnosed with a CNST, and approximately 190,000 died, ranking CNSTs in the top 10 mortalities caused by cancer.<sup>5,6,7</sup> More than 120 CNST entities have been classified by the World Health Organization (WHO) based on their clinicopathological characteristics and histological patterns.<sup>8</sup> The signs and symptoms for CNSTs depend on the tumor location, and they are not exclusively indicative of the presence of these tumors.<sup>3,9,10</sup> Causes associated with the development of CNSTs vary, and many are still under investigation.<sup>11-20</sup> Many studies that assess health public awareness rely on random sampling through telephone directories, a system that is not necessarily available in many developing countries. Questionnaires provided online have frequently been used, including in marketing research and psychological studies. Due to their attractive ability to access larger cohorts and improve validation checks, and thus data quality, these Web-based questionnaires represent an important tool for many epidemiological studies on public health.<sup>21,22</sup> Awareness of the symptoms and risk factors for CNSTs is especially critical, since the disease signs tend to be vague and easily overlooked, resulting in a delayed response to take appropriate action. Unfortunately, there is a lack of CNST awareness studies that assess the level of public understanding in many regions of the world. In this study, we aimed to investigate the knowledge concerning CNST signs and symptoms and risk factors, as well as readiness to seek medical advice, among citizens of the Kingdom of Saudi Arabia (KSA) using 2 questionnaire delivery methods.

**Methods. Subjects and study design.** This was a cross-sectional survey using 2 delivery methods, distributed in parallel between June 2015 and June 2016.

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Personally delivered self-administered questionnaires were distributed (1,752 forms) until 1,500 occupants of Jeddah, KSA, completed the forms. A nonprobability sampling technique was used to recruit participants from the local university and its local hospital, families and friends of participating students, workers, and customers visiting local markets and no exclusion criteria of the participants was applied. This sample size provided a confidence level of 95%, with a confidence interval (CI) of 2.53%, for a population size of 3,976,000 people in Jeddah, as reported in Statistical Yearbook 50 (2014) published by the Central Department of Statistics and Information.<sup>23</sup> Fourth-year applied medical sciences students were involved in recruiting participants, and they were trained prior to delivering the questionnaire. The same questionnaire was activated online in Arabic. The questionnaire was advertised through Twitter, Instagram, and email. The participants were recruited until 1,500 self-administered questionnaires were completed. This number was chosen to allow for statistical comparisons with the personally delivered questionnaires.

**Questionnaire items.** The structure and items for the questionnaire were developed in English based on the Cancer Awareness Measure (CAM) and information in the literature for CNST-specific symptoms and risk factors, as mentioned above.<sup>24</sup> The items were then translated into Arabic, and the questionnaires were made available in both languages for the participants to choose from. All items were reviewed by 2 neuro-oncologists to ensure relevance and accuracy. The participants were not allowed to rewrite their recall items once they proceeded to the next question. The items included the following:

**Section 1.** This section comprising the 2 following questions, addressed the participants knowledge about the CNST warning signs and symptoms: Question 1) An open, unprompted warning sign question: "Would you please name as many early warning signs of CNST as you can think of?"; Question 2) A closed, prompted warning sign question: "Can you state whether you think any of these are warning signs of CNST? Do you think X could be a sign/symptom of CNST?" Here, X was one of 19 signs/symptoms, namely headaches, not eating or having a poor appetite, loss of weight, vomiting without diarrhea, experiencing abnormal involuntary movements, loss of bladder/bowel control, drowsiness or prolonged sleepiness, back pain or stiffness, odd posture, unusual head tilt or stiff neck, arm paralysis, monoplegia, muscle weakness, visual impairment, deafness, excessive emotional problems, behavioral problems, personality change, constant confusion, and

clumsiness or loss of balance. For children, further symptoms were mentioned, such as congenital anomaly of the brain, enlarged head development, physical delay, and difficulty in awareness and learning. For this prompted question, the response options were “Yes”/“No”/“Don’t know”.

**Section 2.** This section addressed barriers to seeking help and was composed of the 2 following questions: Question 3) An open, unprompted question on help-seeking behavior: “If you had a symptom that you thought might be a sign of a CNST, how soon would you contact your doctor to make an appointment to discuss it?”; Question 4) A closed, prompted question on barriers to seeking help: “Sometimes, people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?” Ten options from CAM were included, and for this closed question, the response options were “Yes, often”/“Yes, sometimes”/“No”/“Don’t know”.

**Section 3.** This section composed of the 2 following questions, addressed knowledge of possible risk factors: Question 5) An open, unprompted risk factor question: “What do you think affects a person’s chance of developing a CNST?”; Question 6) A closed, prompted risk factor question: “These are some of the factors that can increase a person’s chance of developing a CNST. How much do you agree that each of the listed factors can increase a person’s chance of developing a CNST?” A list of 13 items was provided, including being over 70 years old, lack of regular exercise, being overweight (body mass index [BMI] over 25), regular exposure to radiation/X-rays or computed tomography (CT) scans, exposure to pesticides, prolonged poor diet, infections, repetitive and prolonged exposure to mobile phones, and familial and syndromic genetic factors. For this prompted question, the response options were given on a 5-point Likert agreement scale (“Strongly agree” to “Strongly disagree”).

**Section 4.** This final section that was designed following CAM, was composed of a set of questions on sociodemographic characteristics, including age, gender, location/residence, ethnicity, marital status, main language, education, employment, and a CNST contact.

**Scoring of items.** The items were scored in the following manner: 1) Unprompted items: For knowledge of signs and symptoms (Q1) and risk factors (Q5), 1 mark was given for unprompted items that also appeared in the corresponding prompt list. For the seeking help open question (Q3), the results were scored on a scale of 1-10 (Immediately=10, 1-3 days/as

soon as possible=9, 4-6 days=8, 1 week=7, 2 weeks=6, 1 month=5, 6 weeks=4, 3 months=3, 6 months=2, 12 months=1, Never/don’t know/unanswered=0); and 2) Prompted items: For the signs and symptoms prompted items (Q2), the responses “No” and “Don’t Know” were scored as 0, with a score of 1 given for each “Yes” response, allowing a maximum possible score of 19. For the risk factor prompted items (Q6), “Not sure,” “Disagree,” and “Strongly disagree” responses were scored as 0, while “Strongly agree” or “Agree” responses were scored as 1, allowing a maximum possible score of 13. The total knowledge score was calculated as the sum of the scores for both questions, giving a maximum possible score of 32. For Q4, each item with responses of “Yes, often” or “Yes, sometimes” was given a score of 1, while item responses of “No”/“Don’t know” or unanswered items were given a score of 0.

**Reliability.** The Cronbach’s alpha coefficient for a pretest analysis for 95 participants for Q2 and 6 was 0.743. Following the collection of all 1,500 personally delivered questionnaires, the reliability coefficient (Cronbach’s alpha) for Q2 was 0.760, while it was 0.728 for Q6 and 0.771 for both. For the online survey, the reliability coefficient (Cronbach’s alpha) for Q2 was 0.791, while it was 0.859 for Q6 and 0.833 for both.

**Data analysis.** An identification number was given for each completed questionnaire. The data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 21.0 (IBM Corp., Armonk, NY, USA) to generate descriptive and inferential statistics, which were used as appropriate. For the sociodemographic characteristics, the data were expressed using frequencies and percentages, and the significance between the groups was calculated using the Pearson chi-square test of independence. Differences between item selections were tested using the chi-square test for independence, with Yates continuity correction. Differences in the knowledge scores obtained within groups were compared using analysis of variance (ANOVA) robust tests of equality of means, and *p*-values for Welch and Brown-Forsythe were indicated. A model of multiple regression analysis was employed to examine the influence of all the sociodemographic characteristics on the total knowledge scores, and missing values were excluded in a pairwise manner. Univariate general linear models (GLMs) that included all participants were used to determine the effects of the delivery method on the knowledge scores while adjusting for sociodemographic factors.

**Results.** The sociodemographic characteristics of all participants are shown in Table 1. Apart from

region and ethnic grouping, there were significant differences between the frequencies in each subgroup when comparing the 2 participant pools, as determined by Pearson's chi-square test of independence. However, the proportions of subgroups within the categories were similar. Compared with the personally delivered method, the sociodemographic characteristics of participants recruited via the online method exhibited a higher number of younger participants (4.6% in person, 13.9% online; mean age: 27.2 years in person, 25.2 years online), females (61.7% in person, 80.5% online), participants who were mostly unemployed (49.2% in person, 72.0% online), and participants who had no CNST contact (63.5% in person, 70.3% online). A similar number of participants in both methods had at least one sociodemographic item undeclared (441 participants [29.4%] in person, 440 participants [29.3%] online).

**Responses to signs and symptoms items and risk factors.** On average, the participants responded to 99.6% of the items on the personally delivered questionnaires, while those who responded online completed 100% of the items (Appendices 1, 2, and 3). The data analysis for all the participants indicated significant differences between the recall and recognition responses (Table 2). The most recalled items were "Headaches" (45.2%), "Drowsiness or prolonged sleepiness" (22.1%), and "Difficulty in awareness and learning" (18.7%); in contrast, the most recognized items were "Headaches" (85.2%), "Abnormal involuntary movements" (84.6%), and "Clumsiness/loss of balance" (79.5%). The average score for the recognition items for the participants was significantly higher than the average score for recall ( $1.9 \pm 1.8$  recall,  $9.4 \pm 3.5$  recognition,  $p < 0.001$ ).

The most recalled risks were "Radioactive location/occupation" (23.8%), "Close relative with CNST" (15.6%), and "Low physical activity" (6.2%), while the most recognized items were "Radioactive location/occupation" (84.1%), "Exposure to pesticides" (70.6%), and "Repetitive long periods of exposure to mobile phones" (65.9%). The average score for the recognition items was significantly higher than the average score for recall ( $0.8 \pm 1.0$  recall,  $5.8 \pm 3.0$  recognition,  $p < 0.001$ ).

**Sociodemographic factors that may influence total knowledge scores.** The average overall knowledge score for the recognized items for all the participants was  $15.3 \pm 5.3$  out of 32 items (47.7%). Analysis of variance (ANOVA) indicated significant differences in the total scores between groups for age, ethnicity, marital status, employment status, and cancer contact (Table 3). Older participants, participants of non-Arab ethnicity, and those who were married, employed, or had cancer

**Table 1 -** Sociodemographic characteristics of all participants.

Characteristics	All participants	Personally delivered	Provided online	$\chi^2$
	n (%)			
<i>Age group</i>				
<18	277 (9.2)	69 (4.6)	208 (13.9)	80.84*
18-39	2318 (77.3)	1142 (76.1)	1176 (78.4)	
40+	291 (9.0)	178 (11.9)	113 (7.5)	
Not declared	114 (3.8)	111 (7.4)	3 (0.2)	
<i>Gender</i>				
Male	781 (26.0)	552 (36.8)	229 (15.3)	170.306*
Female	2134 (71.1)	926 (61.7)	1208 (80.5)	
Not declared	85 (2.8)	22 (1.5)	63 (4.2)	
<i>Region</i>				
Riyadh	476 (15.9)	0 (0)	476 (31.7)	1189.797*
Jeddah	2145 (21.5)	1500 (100)	645 (43)	
South	72 (2.4)	0 (0)	72 (4.8)	
North	72 (2.4)	0 (0)	72 (4.8)	
East	189 (6.3)	0 (0)	189 (12.6)	
Outside KSA	40 (1.4)	0 (0)	40 (2.7)	
Not declared	6 (0.2)	0 (0)	6 (0.4)	
<i>Ethnic group</i>				
Arab	2251 (75.0)	1094 (72.9)	1157 (77.1)	0.682
Other	126 (4.2)	66 (4.4)	60 (4.0)	
Not declared	623 (20.8)	340 (22.7)	283 (18.9)	
<i>Language</i>				
Arabic	2907 (96.9)	1423 (94.9)	1484 (98.9)	24.187
English	47 (1.6)	40 (2.7)	7 (0.5)	
Not declared	46 (1.5)	37 (2.5)	9 (0.6)	
<i>Marital status</i>				
Single	1745 (58.2)	851 (56.7)	894 (59.6)	8.638*
Married	1131 (37.7)	615 (41.0)	516 (34.4)	
Not declared	124 (4.1)	34 (2.3)	90 (6.0)	
<i>Highest level of education</i>				
None	21 (0.7)	14 (0.9)	7 (0.5)	25.608*
<University	1010 (33.7)	497 (33.1)	513 (34.2)	
≥University	1894 (63.1)	943 (62.9)	951 (63.4)	
Other	23 (0.8)	23 (1.5)	0 (0.0)	
Not declared	52 (1.7)	23 (1.5)	29 (1.9)	
<i>Work status</i>				
Employed	1107 (36.9)	733 (48.9)	374 (24.9)	180.668*
Unemployed	1818 (60.6)	738 (49.2)	1080 (72.0)	
Not declared	75 (2.5)	29 (1.9)	46 (3.1)	
<i>CNST contact</i>				
Yes	893 (29.8)	471 (31.4)	422 (28.1)	6.908*
No	2006 (66.9)	952 (63.5)	1054 (70.3)	
Not declared	101 (3.40)	77 (5.1)	24 (1.6)	

CNST - Central nervous system tumor, KSA - Kingdom of Saudi Arabia.

Pearson Chi-Square test for independence comparing characteristics for participants recruited via the personally delivered versus the online provided method. \*represents significance  $p < 0.05$

**Table 2 -** Frequencies of participants' agreements with statements associated with the signs and symptoms or risk factors for central nervous system tumors.

Factor	All Participant		
	Recall	Recognition	$\chi^2$ <sup>a</sup>
	n (%)		
<i>Signs and symptoms</i>			
Headaches	1355 (45.2)	2555 (85.2)	1059.96*
Drowsiness or prolonged sleepiness	663 (22.1)	1700 (56.7)	756.51*
Difficulty in awareness and learning	560 (18.7)	1702 (56.7)	927.35*
Arm paralysis, muscle weakness	520 (17.4)	1550 (51.7)	783.91*
Visual impairment	466 (15.5)	1924 (64.1)	1486.99*
Abnormal involuntary movements	407 (13.6)	2538 (84.6)	3035.04*
Back pain, back stiffness, odd posture	384 (12.8)	1066 (35.5)	423.37*
Vomiting without diarrhea	307 (10.2)	1086 (36.2)	567.74*
Clumsiness/loss of balance	305 (10.2)	2386 (79.5)	2921.82*
Loss of weight	169 (5.6)	1644 (54.8)	1718.13*
Not eating or having a poor appetite	162 (5.4)	1674 (55.8)	1801.30*
Deafness	109 (3.6)	1507 (50.2)	1654.32*
Excessive emotional problems	102 (3.4)	701 (23.4)	515.36*
Enlarged head development	97 (3.2)	1435 (47.8)	1572.42*
Behavior problems, personality change	94 (3.1)	710 (23.7)	545.48*
Unusual head tilt or stiff neck	29 (0.97)	1441 (48.0)	1796.03*
Congenital anomaly of brain	19 (0.6)	1126 (37.5)	1324.35*
Physical delay	9 (0.3)	1133 (37.8)	1365.98*
Loss of bladder/bowel control	8 (0.3)	435 (14.5)	443.91*
Average score (SD) out of 19	1.92 ( $\pm$ 1.8)	9.44 ( $\pm$ 3.53)	$p=0.000$
<i>Risk factors</i>			
Radioactive location/occupation	713 (23.8)	2524 (84.1)	2206.50*
Close relative with CNST	469 (15.6)	1454 (48.5)	778.31*
Low physical activity	186 (6.2)	737 (24.6)	413.52*
Repetitive long periods of exposure to mobile phones	158 (5.3)	1976 (65.9)	2424.47*
Low fruit and vegetable intake	288 (4.8)	760 (12.7)	256.48*
Frequent exposure to bisphenol A	109 (3.6)	1956 (65.2)	2530.19*
Red/processed meat	216 (3.6)	650 (10.8)	257.28*
Frequent exposure to dental X-rays	79 (2.6)	1294 (43.1)	1409.94*
Exposure to computed tomography (CT) scans	45 (1.5)	1390 (46.3)	1671.51*
Infection	43 (1.4)	580 (19.3)	569.11*
Overweight (body mass index [BMI] over 25)	40 (1.3)	938 (31.3)	998.31*
Exposure to pesticides	36 (1.2)	2117 (70.6)	3149.27*
Over 70 years of age	25 (0.8)	1069 (35.6)	1239.57*
Average score (STD) out of 13	0.80 ( $\pm$ 1.04)	5.82 ( $\pm$ 3.04)	$p=0.000$

\*Chi-Square test for independence with Yates continuity correction. \*represents significance  $p < 0.05$ , \*P-values for ANOVA Welch and Brown-Forsythe

contacts were found to have higher scores. The multiple regression analysis model that considered all the sociodemographic factors (apart from region) indicated that employment and cancer contact were significant predictors of overall knowledge scores ( $p < 0.05$ ).

The means of the overall knowledge scores for recognized items for personally delivered and online questionnaires were significantly different

( $14.5 \pm 4.97$  in person,  $15.9 \pm 5.44$  online; ANOVA,  $p < 0.001$ ). To determine the effect of the questionnaire delivery method on the knowledge scores, univariate GLM models were used to adjust for differences in sociodemographic characteristics. The initial analysis showed interactions in the sociodemographic characteristics of education, gender, and marital status; thus, these items were excluded. The analysis for all

participants indicated that differences observed in the overall knowledge scores between the 2 participant pools were due to the differences between the 2 sociodemographic compositions (method adjusted for age, ethnicity, language, employment status, cancer contact; means: 16.1±0.6 in person, 17.2±0.5 online;  $F=2.204$ ,  $p=0.138$ ).

**Recognized items for barriers to seeking help.** The data collected for all the participants indicated that the top 3 recognized items for barriers to seeking help were “Worry about what the doctor might find” (74.0%) and “Too scared” (67.6%; Table 4). The data for all the participants showed that those who were willing to see their doctors within a week scored significantly higher for their knowledge scores than those who did not think an action was ever required (mean knowledge score for those who declared taking action within a week:

15.4±5.3,  $N=2,038$ ; mean knowledge score for those who declared taking action after a week: 15.4±5.0,  $n=598$ ; mean knowledge scores for those who would not take action: 14.2±5.7,  $n=364$ ; Brown-Forsythe ANOVA,  $p<0.005$ ).

**Discussion. Main findings of this study.** This study showed low awareness of the signs and symptoms of CNSTs, as well as associated risk factors, among participants residing in the KSA. The data highlighted concerns associated with anticipated delays in seeking medical advice, including being scared and facing a diagnosis, and showed a relationship between the willingness to act and the level of CNST knowledge. In addition, this work showed that using 2 approaches to deliver a questionnaire - personal delivery and online

**Table 3 -** Influence of sociodemographic factors on total knowledge scores for prompted signs and symptoms and risk factor items.

Sociodemographic Characteristic	Mean total score out of 32	P-value	All participants			
			Multiple regression analysis			
			Beta	P-value	95% confidence interval	
				Lower	Upper	
<i>Age</i>						
<18	14.37	0.004*	0.030	0.211	-0.203	0.922
18-39	15.37					
40+	15.65					
<i>Gender</i>						
Male	15.60	0.058	-0.019	0.444	-0.788	0.346
Female	15.16					
<i>Ethnicity</i>						
Arab	15.34	0.017*	0.032	0.173	-0.327	1.81
Other	16.46					
<i>Language</i>						
Arabic	15.25	0.102	0.026	0.261	-0.825	3.04
English	16.89					
<i>Marital status</i>						
Single	14.99	0.000*	0.020	0.389	-0.277	0.712
Married	15.71					
<i>Education</i>						
No qualifications	15.00	0.184	0.004	0.856	-0.407	0.490
<University	15.07					
≥University	15.41					
Other	13.13					
<i>Employment status</i>						
Employed	15.86	0.000*	-0.088	0.001*	-1.50	-0.409
Unemployed	14.92					
<i>Cancer contact</i>						
Yes	15.97	0.000*	-0.082	0.000*	-1.39	-0.475
No	14.94					

P-values for ANOVA Welch and Brown-Forsythe. \*represents significance  $p<0.05$

**Table 4 -** Participants' agreement with statements associated with barriers to seeking help.

Barriers to seeking help	All participants	
	n	(%)
Worried about what the doctor might find	2220	(74.0)
Too scared	2029	(67.6)
Difficult to make an appointment with the doctor	1737	(57.9)
Too busy to make time to go to the doctor	1521	(50.7)
Have too many other things to worry about	1503	(50.1)
Difficult to arrange transport to the doctor's clinic	1389	(46.3)
Difficult to talk to the doctor	1113	(37.1)
Too embarrassed	671	(22.4)
Do not feel confident talking about my symptoms with the doctor	618	(20.6)
Worried about wasting the doctor's time	402	(13.4)

access - could widen the composition of participants and provide an alternative for questionnaire distribution in areas where there is a lack of directories.

**What is already known about this topic.** An extensive search of the literature highlighted only 3 studies concerned specifically with CNST public awareness worldwide.<sup>3,25</sup> Other published studies for cancer awareness in the KSA have focused on non-specified cancer awareness, breast cancer, colorectal cancer, and oral cancer.<sup>26-30</sup> Comparable to the data from this study, the top recognized warning signs of brain tumors in the United Kingdom were vomiting and headaches.<sup>3</sup> Recently, the frequencies of symptoms experienced by CNST patients were investigated.<sup>10</sup> The most widespread symptoms were fatigue and feeling drowsy, while the least frequently experienced were nausea, vomiting, and dyspnea.

Unfortunately, no studies assessing the public perception of risk factors for CNST were found. Most studies addressed risk factors in the context of general cancer awareness.<sup>31-33</sup> The top recognized cancer-associated risk factors include smoking, stress, low vegetable and high alcohol intake, lifestyle, and genetics. In the KSA, the top-ranked recognized cancer risk factors were tobacco, alcohol, and intake of fruit and vegetables.<sup>27</sup>

Knowledge of general cancer awareness has been previously shown to be influenced by employment or cancer contact.<sup>27,34</sup> In addition, increased knowledge has previously been associated with a lower anticipated delay in requesting medical advice.<sup>35</sup> However, many barriers for such action, including fear, are still highly reported in cancer awareness studies.<sup>34,36</sup>

**What this study adds.** This is the first study in the region to report on public awareness for CNSTs, and

it is one of the few similar publications. Unlike those of many cancers, such as breast cancer or melanoma, the signs and symptoms of CNST can be vague, and lack of recognition could lead to a lower quality of life and possible fatality.<sup>3,9,10</sup> The level of awareness for specific signs and symptoms associated with CNSTs, such as excessive emotional problems, enlarged head development, behavioral problems, personality change, unusual head tilt or stiff neck, or congenital anomaly of the brain, are not necessarily addressed in cancer awareness studies.<sup>27,34,35</sup> Indeed, in this research, these vital signs were shown to be less frequently recognized. These data highlight the wide gap between the public perception of CNST-associated symptoms and their actual frequencies of occurrence. Thus, the work indicates a need for professional awareness programs to improve public awareness concerning the signs and symptoms associated with CNSTs.

The data presented here show that the personally modifiable risk factors, such as eating processed food, low intake of fruits and vegetables, exercising, and monitoring weight, were least recognized. In contrast, less-modifiable risk factors, such as exposure to radiation and pesticides, were more recognized. Collectively, and in contrast to what is perceived for cancer risks, an underlying belief that risks for CNSTs are mainly nonmodifiable may be present.

Compared with recent cancer awareness studies, the means of the total knowledge scores for CNST awareness reported in this study were low, with the participants receiving less than 50% of the total possible scores.<sup>27,34,36</sup> The most recognized barriers out of all the recognized items were "Worry about what the doctor might find" and being "Too scared." Participants who were willing to see their doctors within a week scored significantly higher for their knowledge than those who did not think an action was ever required. These outcomes indicate that, in addition to improving knowledge, cancer and CNST awareness campaigns could benefit from targeting fears, perhaps by emphasizing the advantages and benefits of early detection, underlining the presence of low-grade cancers that are associated with high recovery rates, and publicizing the improvements seen in current treatment outcomes. Perhaps a philosophy of "Better check it out" should be more effectively endorsed, as delays in seeing the doctor could allow for the progression of cancer aggressiveness.

The work presented here also showed that the frequencies for sociodemographic characteristics were significantly different for the 2 participant pools recruited using the different delivery methods. More

participants that were under 18 years old, as well as those that were unemployed, were recruited online. Thus, the method of delivery appears to influence the sociodemographic composition of participants.

**Limitations of this study.** Some limitations were associated with the structure of the instrument. Many cancer awareness studies that have used CAM or based their instrumentation on CAM rely on recognition items to estimate the level of knowledge and awareness. However, variation in the significance between recall and recognition for individual items has been seen in previous studies, and different rankings of risk factor items for recall and recognition in the same population have previously been reported.<sup>31,37</sup> Thus, it is difficult to determine which better captures the concept of cancer awareness. Another limitation of the instrument is related to risk factor items presented as associated with CNSTs. Many of these items are still being investigated at a global level, and they have several associated controversies. Excluded items, such as smoking and environmental pollution, have recently been investigated in relation to CNSTs.<sup>38-40</sup>

The limitations associated with the distribution methods included the inability to report the willingness to participate in the survey, and thus, being unable to record information for non-responders. This may have resulted in a bias toward participants who are naturally responsive. However, it is worth noting that some participants were reluctant to act following disease sign detection, suggesting the inclusion of some disinclined participants. Unfortunately, no national population database listing of households in the local government area was available; thus, the study design was limited to a nonprobability sampling technique. Consequently, this survey, like other cancer awareness investigations in the KSA, had an underlying partiality for including mainly young, educated females, raising concerns about the lack of involvement of males and the elderly.<sup>26-30,41</sup> This lack of involvement could be a potential barrier for the improvement of cancer and CNST awareness for these groups. Thus, there is a need to create a national population database in the KSA that can be utilized for health-related studies.

## References

- Green T, Atkin K, Macleod U. GPs' perceptions and experiences of public awareness campaigns for cancer: a qualitative enquiry. *Health Expect* 2016; 19: 377-387.
- Dixon HG, Pratt IS, Scully ML, Miller JR, Patterson C, Hood R, et al. Using a mass media campaign to raise women's awareness of the link between alcohol and cancer: cross-sectional pre-intervention and post-intervention evaluation surveys. *BMJ open* 2015; 5: e006511.
- HeadSmart Be Brain Tumour A. A new clinical guideline from the Royal College of Paediatrics and Child Health with a national awareness campaign accelerates brain tumor diagnosis in UK children-"HeadSmart: Be Brain Tumour Aware". *Neuro Oncol* 2016; 18: 445-454.
- de Ruiter MA, Schouten-van Meeteren AY, van Vuurden DG, Maurice-Stam H, Gidding C, Beek LR, et al. Psychosocial profile of pediatric brain tumor survivors with neurocognitive complaints. *Qual Life Res* 2016; 25: 435-446.
- Dolecek TA, Propp JM, Stroup NE, Kruchko C. CBTRUS statistical report: primary brain and central nervous system tumors diagnosed in the United States in 2005-2009. *Neuro Oncol* 2012;14: v1-49.
- Ostrom QT, Gittleman H, Fulop J, Liu M, Blanda R, Kromer C, et al. CBTRUS statistical report: primary brain and central nervous system tumors diagnosed in the United States in 2008-2012. *Neuro Oncol* 2015; 17: iv1-iv62.
- Ferlay J, Soerjomataram I, Dikshit R, Eser S, Mathers C, Rebelo M, et al. Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer* 2015; 136: E359-386.
- Louis DN, Perry A, Reifenberger G, von Deimling A, Figarella-Branger D, Cavenee WK, et al. The 2016 world health organization classification of tumors of the central nervous system: a summary. *Acta neuropathol* 2016; 131: 803-820.
- Diamond EL, Russell D, Kryza-Lacombe M, Bowles KH, Applebaum AJ, Dennis J, et al. Rates and risks for late referral to hospice in patients with primary malignant brain tumors. *Neuro Oncol* 2016; 18: 78-86.
- Armstrong TS, Vera-Bolanos E, Acquaye AA, Gilbert MR, Ladha H, Mendoza T. The symptom burden of primary brain tumors: evidence for a core set of tumor- and treatment-related symptoms. *Neuro Oncol* 2016; 18: 252-260.
- Wu S, Powers S, Zhu W, Hannun YA. Substantial contribution of extrinsic risk factors to cancer development. *Nature* 2016; 529: 43-47.
- Sergentanis TN, Tsvigoulis G, Perlepe C, Ntanasis-Stathopoulos I, Tzanninis IG, Sergentanis IN, et al. Obesity and risk for brain/CNS tumors, gliomas and meningiomas: A meta-analysis. *PLoS One* 2015; 10: e0136974.
- Braganza MZ, Kitahara CM, Berrington de Gonzalez A, Inskip PD, Johnson KJ, Rajaraman P. Ionizing radiation and the risk of brain and central nervous system tumors: a systematic review. *Neuro Oncol* 2012; 14: 1316-1324.
- Claus EB, Calvocoressi L, Bondy ML, Schildkraut JM, Wiemels JL, Wrensch M. Dental x-rays and risk of meningioma. *Cancer* 2012; 118: 4530-4537.
- Searles Nielsen S, McKean-Cowdin R, Farin FM, Holly EA, Preston-Martin S, Mueller BA. Childhood brain tumors, residential insecticide exposure, and pesticide metabolism genes. *Environ Health Perspect* 2010; 118: 144-149.
- Huncharek M. Maternal intake of N-nitroso compounds from cured meat and the risk of pediatric brain tumors: a review. *J Environ Pathol Toxicol Oncol* 2010; 29: 245-253.
- Kofman A, Marcinkiewicz L, Dupart E, Lyshchev A, Martyynov B, Ryndin A, et al. The roles of viruses in brain tumor initiation and oncomodulation. *J Neurooncol* 2011; 105: 451-466.
- Morgan LL, Miller AB, Sasco A, Davis DL. Mobile phone radiation causes brain tumors and should be classified as a probable human carcinogen (2A) (review). *Int J Oncol* 2015; 46: 1865-1871.

19. Hardell L, Carlberg M. Mobile phone and cordless phone use and the risk for glioma - Analysis of pooled case-control studies in Sweden, 1997-2003 and 2007-2009. *Pathophysiology* 2015; 22: 1-13.
20. Pouchieu C, Baldi I, Gruber A, Bertheaud E, Carles C, Loiseau H. Descriptive epidemiology and risk factors of primary central nervous system tumors: Current knowledge. *Rev Neurol (Paris)* 2016; 172: 46-55.
21. Hamilton JG, Breen N, Klabunde CN, Moser RP, Leyva B, Breslau ES, et al. Opportunities and challenges for the use of large-scale surveys in public health research: a comparison of the assessment of cancer screening behaviors. *Cancer Epidemiol Biomarkers Prev* 2015; 24: 3-14.
22. van Gelder MM, Bretveld RW, Roeleveld N. Web-based questionnaires: the future in epidemiology? *Am J Epidemiol* 2010; 172: 1292-1298.
23. Central Department of Statistics and Information. Statistical Yearbook 50 (2014). [Access date 2015 February; Checked date 2018 June] Available from: <https://www.stats.gov.sa/en/1163>.
24. Stubbings S, Robb K, Waller J, Ramirez A, Austoker J, Macleod U, et al. Development of a measurement tool to assess public awareness of cancer. *Br J Cancer* 2009; 101: S13-S17.
25. Whittle IR, Broadbent M, Boyd A, Lahiri S, Robbins A, Klutting R, et al. Public perceptions of brain tumours in Scotland: the need for access to appropriate information. *Scott Med J* 1996; 41: 87-9.
26. Abolfotouh MA, BaniMustafa AA, Mahfouz AA, Al-Assiri MH, Al-Juhani AF, Alaskar AS. Using the health belief model to predict breast self examination among Saudi women. *BMC Public Health* 2015; 15: 1163.
27. Ravichandran K, Mohamed G, Al-Hamdan NA. Public knowledge on cancer and its determinants among Saudis in the Riyadh Region of Saudi Arabia. *Asian Pac J Cancer Prev* 2010; 11: 1175-1180.
28. Radi SM. Breast cancer awareness among Saudi females in Jeddah. *Asian Pac J Cancer Prev* 2013; 14: 4307-4312.
29. Khayyat YM, Ibrahim EM. Public awareness of colon cancer screening among the general population: A study from the Western Region of Saudi Arabia. *Qatar Med J* 2014; 2014: 17-24.
30. Zubaidi AM, AlSubaie NM, AlHumaid AA, Shaik SA, AlKhayal KA, AlObeed OA. Public awareness of colorectal cancer in Saudi Arabia: A survey of 1070 participants in Riyadh. *Saudi J Gastroenterol* 2015; 21: 78-83.
31. Ryan AM, Cushen S, Schellekens H, Bhuachalla EN, Burns L, Kenny U, et al. Poor awareness of risk factors for cancer in Irish adults: results of a large survey and review of the literature. *Oncologist* 2015; 20: 372-378.
32. Lagerlund M, Hvidberg L, Hajdarevic S, Fischer Pedersen A, Runesdotter S, Vedsted P, et al. Awareness of risk factors for cancer: a comparative study of Sweden and Denmark. *BMC Public Health* 2015; 15: 1156.
33. Marlow LA, Robb KA, Simon AE, Waller J, Wardle J. Awareness of cancer risk factors among ethnic minority groups in England. *Public Health* 2012; 126: 702-709.
34. Niksic M, Racher B, Warburton FG, Wardle J, Ramirez AJ, Forbes LJ. Cancer symptom awareness and barriers to symptomatic presentation in England--are we clear on cancer? *Br J Cancer* 2015; 113: 533-542.
35. Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Waller J, et al. Public awareness of cancer in Britain: a population-based survey of adults. *Br J Cancer* 2009; 101: S18-23.
36. Hubbard G, Macmillan I, Canny A, Forbat L, Neal RD, O'Carroll RE, et al. Cancer symptom awareness and barriers to medical help seeking in Scottish adolescents: a cross-sectional study. *BMC Public Health* 2014; 14: 1117.
37. Power E, Wardle J. Change in public awareness of symptoms and perceived barriers to seeing a doctor following Be Clear on Cancer campaigns in England. *Br J Cancer* 2015; 112: S22-26.
38. Huang Y, Huang J, Lan H, Zhao G, Huang C. A meta-analysis of parental smoking and the risk of childhood brain tumors. *PloS One* 2014; 9: e102910.
39. Lachance DH, Yang P, Johnson DR, Decker PA, Kollmeyer TM, McCoy LS, et al. Associations of high-grade glioma with glioma risk alleles and histories of allergy and smoking. *Am J Epidemiol* 2011; 174: 574-581.
40. Spycher BD. Air pollutants associated with astrocytoma and medulloblastoma. *J Pediatr* 2016; 170: 341-344.
41. Hussein DM, Alorf SH, Al-Sogaih YS, Alorf SH, Alaskar RS, Al-Mahana AM, et al. Breast cancer awareness and breast self-examination in Northern Saudi Arabia. A preliminary survey. *Saudi Med J* 2013; 34: 681-688.

**Appendix 1** - Participants' responses to prompted question for signs and symptoms of CNS tumors.

Signs and Symptoms	Method of Administration											
	Personal			Online								
	Y	N	DK	Y	N	DK						
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)						
Not eating or having a poor appetite	908	60.5	329	21.9	252	16.8	766	51.1	428	28.5	306	20.4
Experiencing abnormal involuntary movements	1223	81.5	158	10.5	114	7.60	1315	87.7	84	5.60	101	6.73
Difficulty in awareness and learning	839	55.9	427	28.5	229	15.3	863	57.5	437	29.1	200	13.3
Congenital anomaly of brain	670	44.7	460	30.7	362	24.1	456	30.4	715	47.7	329	21.9
Drowsiness or prolonged sleepiness	857	57.1	357	23.8	275	18.3	843	56.2	393	26.2	264	17.6
Think back pain, back stiffness, odd posture	577	38.5	591	39.4	327	21.8	489	32.6	676	45.1	335	22.3
Excessive emotional problems	390	26.0	784	52.3	321	21.4	311	20.7	889	59.3	300	20.0
Arm paralyzed, monoplegia, muscle weakness	782	52.1	370	24.7	343	22.9	768	51.2	439	29.3	293	19.5
Physical delay	612	40.8	513	34.2	371	24.7	521	34.7	636	42.4	343	22.9
Unusual head tilt or stiff neck	686	45.7	438	29.2	372	24.8	755	50.3	435	29.0	310	20.7
Clumsiness loss of balance	1125	75.0	192	12.8	179	11.9	1261	84.1	127	8.47	112	7.47
Deafness	684	45.6	469	31.3	345	23.0	823	54.9	422	28.1	255	17.0
Headaches	1220	81.3	150	10.0	127	8.47	1335	89.0	79	5.27	86	5.73
Visual impairment	870	58.0	343	22.9	276	18.4	1054	70.3	281	18.7	165	11.0
Enlarged head development	727	48.5	349	23.3	416	27.7	708	47.2	459	30.6	333	22.2
Loss of bladder/bowel control	269	17.9	660	44.0	561	37.4	166	11.1	861	57.4	473	31.5
Behaviour problems, personality change, constant confusion	374	24.9	631	42.1	486	32.4	336	22.4	776	51.7	388	25.9
Vomiting without diarrhoea	512	34.1	487	32.5	496	33.1	574	38.3	572	38.1	354	23.6
Loss of weight	787	52.5	351	23.4	361	24.1	857	57.1	369	24.6	274	18.3

Y - yes, N - no, DK - do not know

**Appendix 2** - Participants' responses to prompted possible risk factors for CNS tumors.

Risk Factors	Method of administration																			
	Personal					Online N (%)														
	SA	A	NS	D	SD	SA	A	NS	D	SD										
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)										
Radioactive location/occupation	716	47.7	487	32.5	231	15.4	53	3.53	12	0.8	1003	66.9	318	21.2	157	10.5	8	0.53	10	0.67
Frequent Exposure to Dental X-Rays	220	14.7	441	29.4	634	42.3	169	11.3	29	1.93	275	18.3	358	23.9	632	42.1	85	5.67	127	8.47
Exposure to CT Scans	240	16.0	463	30.9	579	38.6	182	12.1	28	1.87	291	19.4	396	26.4	612	40.8	66	4.40	118	7.78
Frequent Exposure BPA (Bisphenol A)	379	25.3	569	37.9	417	27.8	114	7.60	20	1.33	531	35.4	477	31.8	395	26.3	30	2.00	56	3.73
Exposure to Pesticides	392	26.1	633	42.2	342	22.8	110	7.33	21	1.40	618	41.2	474	31.6	327	21.8	28	1.87	44	2.93
Repetitive long period exposure to mobile phones	351	23.4	592	39.5	404	26.9	121	8.07	30	2.00	584	38.9	449	29.9	352	23.5	37	2.47	60	4.00
Low fruit and vegetable intake	84	5.60	212	14.1	467	31.1	531	35.4	202	13.5	91	6.07	373	24.9	587	39.1	116	7.73	251	16.7
Red/processed meat	60	4.00	168	11.2	530	35.3	577	38.5	163	10.9	84	5.60	338	22.5	633	42.2	136	9.07	251	16.7
Overweight (BMI over 25)	102	6.80	227	15.1	535	35.7	516	34.4	112	7.47	199	13.3	410	27.3	545	36.3	113	7.53	201	13.4
Over 70 years of age	120	8.00	289	19.3	472	31.5	480	32.0	132	8.80	244	16.3	416	27.7	523	34.9	106	7.07	169	11.3
Close relative with CNST	214	14.3	363	24.2	326	21.7	411	27.4	182	12.1	389	25.9	488	32.5	314	20.9	87	5.80	159	10.6
Infection	67	4.47	113	7.53	283	18.9	556	37.1	474	31.6	91	6.07	309	20.6	413	27.5	134	8.93	321	21.4
Low physical activity	87	5.80	130	8.67	414	27.6	569	37.9	300	20.0	154	10.3	366	24.4	517	34.5	112	7.47	241	16.1

SA - strongly agree, A - agree, NS - not sure, D - disagree, SD - strongly disagree, BMI - body mass index, CNST - central nervous system tumor

**Appendix 3** - Participants' responses to statements associated with barriers to seeking help.

Barriers to seeking help	Method of administration											
	Y		Personal N		DK		Y		Online N (%)		DK	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Too embarrassed	430	28.7	1034	68.9	33	2.20	241	16.1	1184	78.9	70	4.70
Too scared	960	64.0	510	34.0	28	1.90	1069	71.3	400	26.7	26	1.70
Worried about wasting the doctor's time	233	15.5	1215	81.0	48	3.20	169	11.3	1277	85.1	45	3.00
Difficult to talk to the doctor	552	36.8	870	58.0	68	4.50	561	37.4	848	56.5	86	5.70
Difficult to make an appointment with the doctor	803	53.5	619	41.3	69	4.60	934	62.3	499	33.3	61	4.10
Too busy to make time to go to the doctor	775	51.7	650	43.3	68	4.50	746	49.7	678	45.2	67	4.50
Have too many other things to worry about	765	51.0	656	43.7	71	4.70	738	49.2	691	46.1	62	4.10
Difficult to arrange transport to the doctor's clinic	651	43.4	765	51.0	79	5.30	738	49.2	692	46.1	68	4.50
Worried about what the doctor might find	1036	69.1	402	26.8	58	3.90	1184	78.9	269	17.9	42	2.80
Do not feel confident talking about my symptom with the doctor	532	35.5	878	58.5	87	5.80	86	5.70	122	8.10	1292	86.1

Y - yes, N - no, DK - do not know