

The trends of cancer patients' perceptions on the causes and risk factors of cancer over time

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ABSTRACT

الأهداف: تقييم التغيير الحاصل في المفاهيم الشائعة لدى مرضى السرطان عن أسباب مرض السرطان و النتائج العلاجية المتوقعة للمرض خلال فترة زمنية مقدارها 10 سنوات (2006-2016).

المنهجية: أجريت دراسة مقطعية مقارنة في قسم الأورام بمدينة الملك عبد العزيز الصحية، حيث تم استطلاع معلومات مجموعتين مستقلتين من مرضى الأورام، المجموعة الأولى تم استطلاعها ما بين العامين 2006-2008م، و المجموعة الثانية ما بين العامين 2016-2018م. و تم بعد ذلك مقارنة مداخلات الدراسة فيما يتعلق بأسباب السرطان والنتائج العلاجية المتوقعة عند العينتين.

النتائج: شملت الدراسة بالمجمل ما مجموعه 1416 مريض، منهم 464 في العينة الأولى و 952 في الثانية. مستوى التعليم و عدم ممارسة أي عمل و نسبة الأورام الصلبة كانت أعلى في العينة الثانية. كان هناك ازدياد ملحوظ فيما يتعلق بالاعتقاد أن الحسد أحد مسببات السرطان بنسبة 1.3% في العينة الأولى و 33.1% في العينة الثانية. و تم أيضاً ملاحظة أن ما نسبته 23.5% من مشمولين في العينة الثانية قد أجابوا إجابات ذات أساس علمي فيما يتعلق بسبب السرطان لديهم مقارنة بنسبة 13.6% في العينة الأولى و هذا الفرق ذو دلالة إحصائية معتبرة ($p < 0.0001$). و عند إجراء التحليل الإحصائي متعدد المتغيرات تبين أن الفئة العمرية الشبابية من الذكور الذين يمارسون عمل يومي كانوا أكثر ميلاً لإعطاء أسباب ذات أساس و سند علمي في إجاباتهم عند سؤالهم عن سبب السرطان لديهم إذا ما قورنوا بغيرهم

الخلاصة: كشفت نتائج هذه الدراسة عن شيوع مفاهيم خاطئة عن أسباب مرض السرطان بين المرضى أنفسهم. و معالجة هذه الظاهرة تستلزم استخدام منهجية منظمة لتثقيف مرضى السرطان والناس بشكل عام.

Objectives: To evaluate patients' perceptions on the causes and outcomes of cancer and the changes observed over a decade (2006-2016) at King Abdulaziz Medical City, Riyadh, Saudi Arabia.

Methods: Patients diagnosed with cancer and treated at King Abdulaziz Medical City, Riyadh, Saudi Arabia, were enrolled in a cross-sectional study. The patients were enrolled in 2 cohorts: cohort 1 from 2006-2008 and cohort 2 from 2016-2018. The trends of the perceptions related to the causes and outcomes of cancer were compared between the 2 cohorts.

Results: In total, 1416 patients were enrolled in the 2 cohorts: cohort 1 included 464 patients and cohort 2 included 952 patients. The patients in cohort 2 had

a higher level of education, higher unemployment rate, and more solid tumors. There was a significant increase in the belief of the "evil eye" as a cause of cancer from 1.3-33.1% between cohort one and cohort 2. A higher proportion (23.5%) of cohort 2 reported scientific causes for cancer, compared to 13.6% in cohort 1 ($p < 0.0001$). Younger age, male gender, having a job, and being in cohort 2 were significantly associated with providing a scientific answer in a multivariate analysis (modeling scientific cause).

Conclusion: In this study, a frequent misperception related to the causes of cancer was revealed. To tackle this issue, a systematic approach towards education for patients and the public is required to minimize the potential detrimental effects on patient care and patient outcomes.

Keywords: cancer perception, awareness, cause of cancer, knowledge, cancer trends

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Cancer is a major healthcare problem, affecting the lives of millions of people annually, with a significant impact on patients, their families, and society. In general, the outcome of those patients depends on several factors including the stage of cancer and timely treatment offered.¹

There are many perceptions and myths regarding cancer prevalent in all societies and cultures. Societal and cultural perceptions related to cancer may result in a delay in seeking treatment or choosing to seek alternative therapy. These misconceptions and stigmas may increase the stress of patients, their families, and be detrimental to the patients' health and overall treatment outcomes.²⁻⁷ Misconceptions may influence the patient's relationship with the family members and social support systems, and it is critical to understand these myths and perceptions to manage them appropriately and to prevent any potential harm or negative consequences.

Literature related to these myths and beliefs in cancer patients in Saudi Arabia is limited.^{8,9} The issue deserves a more in-depth study, especially the evolution of how these perceptions develop over time in relation to the impact of the communication and social media revolution on society. In this study, the perceptions of cancer patients in Saudi Arabia on the causes and outcomes of cancer were evaluated and compared over a decade.

Methods. This is a secondary analysis for the data of 2 cross-sectional studies, these studies were carried out initially to measure the prevalence of using complementary and alternative medicine among cancer patients. The first study, cohort 1: patients enrolled from 2006-2008 and, the second study cohort 2: from 2016-2018. Both studies were approved by the Institutional Review Board of King Abdulaziz Medical City, Riyadh, Saudi Arabia (no.: RC06/015 and RC16/165/R), and informed consents were obtained from all participants prior to their enrollment. The targeted patients were patients with cancer diagnoses and treated at the Oncology Department, King Abdulaziz Medical City, Ministry of National Guard Health Affairs, Riyadh, Saudi Arabia. The inclusion criteria were any adult patients with cancer who are willing to participate in the study. The study was carried out in accordance with the Declaration of Helsinki and adhered to Good Clinical Practice guidelines.

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The tool was a questionnaire that gathered demographic information such as age, gender, and education level. The questionnaire also included disease information, such as type of cancer and stage. The perceptions from the patients related to the causes of cancer, curability, and the utilization of complementary and alternative medicine (CAM) were also recorded. The tool and results regarding the trends in CAM use was published previously.¹⁰

Statistical analysis. Research coordinators administered the questionnaire, completed the questionnaire and transferred the data in an Excel database. The analysis was carried out using Statistical Analysis System software 9.4 (2016 by SAS® Institute Inc., Cary, NC, USA). Descriptive statistics were used to determine patients' characteristics and the type of perceptions they have. We divided the causes of cancer into 3 categories. Category one included mythical causes which do not have any scientific evidence to support them (jealousy/envy, evil eye, evil spirit, cursed by someone, depression, fate, medication, surgery, trauma, allergy, stress, and giving birth). Category 2 included scientific causes (well-described factors known to cause cancer). Category 3 included lack of knowledge identified by respondents who answered "I don't know". The association between the different perceptions and demographic variables was analyzed.

Our primary objective is to characterize the change in patients' perceptions over time and the factors that influence change. To determine the factors associated with different cohorts, the study participants were divided into 2 cohorts based on the time when the data was collected. The 2 cohorts: cohort 1 (2006-2008) and cohort 2 (2016-2018) were compared using Chi-square or Fisher exact test for categorical factors and t-test or Kruskal-Wallis test for continuous variables as appropriate.

To understand the predictors of a scientific cause response, a multivariate multinomial logistic regression model was used where the cancer cause (scientific, mythical, and lack of knowledge) answer was modeled as the dependent variable and all the potential factors (gender, age, education level, type of cancer) were included as the independent variables. Multivariate ordinal logistic regression models were also carried out for the other outcomes of interest, namely, whether cancer is treatable and if cancer is contagious. The patients responded either "yes, occasionally, or no".

Results. In total, 1416 patients were enrolled in the study in both cohorts; 464 patients in cohort 1 and 952 patients in cohort 2. Patients' characteristics are included in **Table 1**. There was no statistical difference

between the 2 cohorts in terms of age, gender, or marital status. However, cohort 2 included more patients with a higher level of education, higher unemployment, more solid tumors, more patients who received radiation therapy, and stem cell transplant.

The patients in cohort 2 were less likely to perceive cancer as curable, compared to cohort 1 (80.5% vs. 89.5%; $p < 0.0001$). More patients in cohort 1 believed that cancer is not contagious (99.6% vs. 97.7%; $p = 0.0071$). In terms of believing in mythical causes, the patients from cohort 2 were less likely to perceive that cancer is caused by envy, depression, fate, and stress, but they were more likely to perceive that the evil eye, an evil spirit, medication or a curse placed by someone cause cancer. There was a significant increase in the belief of the evil eye as a cause for cancer from 1.3% (cohort 1) to 33.1% (cohort 2) (Table 2). Cohort 2 participants were more likely to state scientific causes of cancer (23.5% vs. 13.6%; $p < 0.0001$), interestingly only 4.5% thought that smoking causes cancer (Table 2).

In a multivariate analysis of the probability of giving a non-scientific vs. a scientific answer, younger age, male gender, employment, patients who tend to perceive that cancer is incurable, and being in cohort 2 were significantly associated with giving a scientific cause answer (Table 3).

In terms of a lack of knowledge of scientific causes, younger age, male gender, CAM use, and being in cohort 2 were associated with the likelihood of giving a scientific answer (Table 4).

The multivariate analysis of the probability of giving a negative answer related to “cancer is contagious” revealed only working status as a significant predictor (Table 5). Giving a negative answer related to “cancer is curable” was only significant in cohort 2 (Table 6).

Discussion. The study revealed that the majority of the sample held mythical beliefs related to the causes of cancer. There was a significant increase in the proportion of patients who reported scientific

Table 1 - Patient’s characteristics.

Characteristics	2006-2008 (n=464)	2016-2018 (n=952)	P-value
<i>Gender</i>			
Male	184 (39.7)	367 (38.5)	0.6890
Female	280 (60.3)	585 (61.4)	
Median age (range)	54 (34-7)	56 (26-8)	0.3840
<i>Marital status (n=1408)</i>			
Married	337 (73.9)	654 (68.7)	0.0857
Single	43 (9.4)	117 (12.3)	
Separated	1 (0.2)	14 (1.5)	
Divorced	13 (2.8)	28 (2.9)	
Widow	62 (13.6)	139 (14.6)	
<i>Level of education (n=1404)</i>			
Illiterate	51 (11.3)	100 (10.5)	<0.0001
Primary	73 (16.1)	162 (17.0)	
Intermediate	188 (41.6)	280 (29.4)	
Secondary	71 (15.7)	243 (25.5)	
Higher education	69 (15.3)	167 (17.5)	
<i>Work status (n=1358)</i>			
No job	328 (70.7)	752 (79.0)	0.0006
Job	136 (29.3)	200 (21.0)	
<i>Disease type (n=1416), as reported by patients</i>			
Solid tumor	342 (73.7)	770 (80.9)	0.0020
Hematological malignancy	122 (26.3)	182 (19.1)	
<i>Treatment type</i>			
Surgery	251 (54.09)	527 (55.36)	0.6541
Radiation	79 (17.03)	417 (43.80)	<0.0001
Chemotherapy	423 (91.16)	780 (81.93)	<0.0001
SCT	0 (0.00)	87 (9.14)	<0.0001
<i>Used CAM</i>			
Yes	449 (96.8)	751 (78.9)	<0.0001
No	15 (3.2)	201 (21.1)	

Values are presented as a number and (%). SCT: stem cell transplant, CAM: complementary and alternative medicine

Table 2 - Perceptions regarding cancer causes and outcome.

Perceptions	n (%)		Difference <i>p</i> -value
	Cohort 1	Cohort 2	
<i>Cancer is contagious:</i>			
Yes (sure, most of the time)	2 (0.4)	7 (0.7)	0.0071
Occasional (occasional, rarely)	0 (0.0)	15 (1.6)	
No	462 (99.6)	930 (97.7)	
<i>Cancer is curable:</i>			
Yes (sure, most of the time)	384 (89.5)	766 (80.5)	<0.0001
Occasional (occasional, rarely)	35 (8.2)	109 (11.4)	
No	10 (2.3)	77 (8.1)	
<i>Cause of cancer:</i>			
<i>Mythical causes*</i>			
Jealousy/envy	138 (29.7)	53 (5.6)	<0.0001
Depression	47 (10.1)	39 (4.1)	<0.0001
Fate	115 (24.8)	193 (20.3)	0.0534
Evil eye	6 (1.3)	315 (33.1)	<0.0001
Medication**	7 (1.5)	53 (5.6)	0.0004
Evil spirit	1 (0.2)	49 (5.1)	<0.0001
Curse	1 (0.2)	16 (1.7)	0.0175
Surgery	1 (0.1)	2 (0.4)	0.2516
Trauma	3 (0.6)	2 (0.2)	0.3381
Stress	10 (2.2)	7 (0.7)	0.0213
Allergy	6 (1.3)	6 (0.6)	0.2233
Giving birth	3 (0.6)	5 (0.5)	0.7218
<i>Scientific causes</i>			
Diet	38 (8.2)	98 (10.3)	0.2071
Infection	7 (1.5)	43 (4.2)	0.0040
Genetic	7 (1.5)	34 (3.6)	0.0298
Smoking	6 (1.3)	43 (4.5)	0.0018
Exposure to radiation	5 (1.1)	37 (3.9)	0.0035
Environment	2 (0.4)	7 (0.7)	0.7262
<i>Cause of cancer: (there is 88 missing values in cohort 2)</i>			
Scientific causes [†]	63 (13.6)	224 (25.9)	<0.0001
Mythical causes [‡]	310 (66.8)	497 (57.5)	
Lack of knowledge [§]	91 (19.6)	143 (16.5)	

Values are presented as a number and (%). Chi-square or Fisher exact test for categorical factors as appropriate. Results from fisher's exact test were used whenever at least one of the cells has an expected count of <5 of the cut-off or significance level of $p < 0.05$. *The authors considered all the reasons that doesn't have strong scientific proof as mythical. **The authors agree that some of the medications may cause cancer but not all. Since the majority of medications do not cause cancer, so we classified by the majority. †Among the multiple answers of the patient if selected one scientific cause, then this case is included in this category. ‡If all of the reported cases by the patients are myths then he is included in this category. §If the patient reported I don't know.

causes for cancer in cohort 2. However, the proportion remains low, less than 25.0%. Being in cohort 2 was an independent factor for reporting scientific causes, which may reflect the impact of improved educational standards, the influence of social media, and the easy access to information.

The awareness of cancer causes and risk factors may vary in populations from different countries. In a study comparing the knowledge of the risk factors for cancer in the population of Sweden and Denmark, the Swedish participants had a higher awareness of 10 of the 13 risk factors studied. More than 90.0% knew that smoking

was a risk factor for cancer. However, less than 50.0% recognized human papillomavirus as a risk factor, which reflects the variation in knowledge, depending on the risk factor.¹¹

In a study with 1330 patients in the United Kingdom, 52.0% of the participants identified the correct causes of cancer, compared to 36.0% who identified mythical causes, with stress the most frequently identified. Younger age, white ethnicity, and higher education predicted the awareness of scientific causes.¹²

Multiple social variables, such as income, educational level, gender, and ethnicity are factors that may

Table 3 - Multivariate multinomial logistic regression analysis: predictors of non-scientific vs. scientific (conditional on the event that the outcome was one of those 2 categories).

Effects	Beta	Odds ratio	Lower confidence interval	Upper confidence interval	P-value
Age	0.00569	1.006	0.996	1.015	0.2412
Gender: female vs. male	0.4657	1.593	1.183	2.145	0.0021
Marital status: married vs. single	-0.1652	0.848	0.615	1.168	0.3120
Educational level: educated vs. uneducated	-0.4200	0.657	0.408	1.058	0.0842
Currently working: yes vs. no	-0.4198	0.657	0.471	0.916	0.0133
Cancer type: hematological malignancy vs. solid tumor	-0.1733	0.841	0.555	1.274	0.4140
CAM use: yes vs. no	-0.2522	0.777	0.518	1.165	0.2219
Infectious disease: occasional vs. no	-0.6215	0.537	0.158	1.822	0.3187
Infectious disease: yes vs. no	-1.1878	0.305	0.059	1.565	0.1547
Disease can be cured: occasional vs. no	1.2805	3.599	1.544	8.387	0.0030
Disease can be cured: yes vs. no	0.6858	1.985	0.973	4.050	0.0594
Surgery: yes vs. no	-0.0401	0.961	0.699	1.319	0.8043
Radiation: yes vs. no	0.0569	1.059	0.775	1.446	0.7204
Chemotherapy: yes vs. no	0.1824	1.200	0.812	1.774	0.3599
SCT: yes vs. no	-0.00540	0.995	0.540	1.832	0.9862
Cohort 2 vs. cohort 1	-0.8646	0.421	0.297	0.598	<.0001

The results of the multinomial logistic regression where the cancer cause (scientific, mythical, and lack of knowledge) answer was modeled as the dependent variable with scientific as reference group and all the factors shown in the table were included as the independent variables. CAM: complementary and alternative medicine, SCT: stem cell transplant, vs.: versus

Table 4 - Multivariate multinomial logistic regression analysis: predictors of lack of knowledge vs. scientific answer (conditional on the event that the outcome was one of those 2 categories).

Effects	Beta	Odds ratio	Lower confidence interval	Upper confidence interval	P-value
Age	0.0222	1.022	1.010	1.035	0.0006
Gender: female vs. male	0.4414	1.555	1.048	2.306	0.0282
Marital status: married vs. single	-0.0883	0.915	0.602	1.393	0.6799
Educational level: educated vs. uneducated	-0.2339	0.791	0.417	1.501	0.4738
Currently working: yes vs. no	-0.2528	0.777	0.497	1.214	0.2673
Cancer type: hematological malignancy vs. solid tumor	0.2609	1.298	0.765	2.203	0.3336
CAM use: yes vs. no	-0.8147	0.443	0.272	0.722	0.0011
Infectious disease: occasional vs. no	-0.5145	0.598	0.109	3.278	0.5535
Infectious disease: yes vs. no	-0.0172	0.983	0.181	5.329	0.9841
Disease can be cured: occasional vs. no	0.2897	1.336	0.482	3.703	0.5775
Disease can be cured: yes vs. no	-0.1702	0.844	0.362	1.967	0.6937
Surgery: yes vs. no	-0.1636	0.849	0.561	1.284	0.4383
Radiation: yes vs. no	0.3840	1.468	0.979	2.201	0.0630
Chemotherapy: yes vs. no	-0.0773	0.926	0.561	1.527	0.7622
SCT: yes vs. no	0.0106	1.011	0.451	2.264	0.9794
Cohort 2 vs. cohort 1	-0.8422	0.431	0.273	0.679	0.0003

The results of the multinomial logistic regression where the cancer cause (scientific, mythical, and lack of knowledge) answer was modeled as the dependent variable with scientific as reference group and all the factors shown in the table were included as the independent variables. CAM: complementary and alternative medicine, SCT: stem cell transplant, vs.: versus

influence the knowledge acquisition related to cancer risk factors.¹³⁻¹⁵ It is unclear why there was a significant increase in the belief of the “evil eye” as a cause for cancer in third of the patients in cohort 2. In a study carried out in 2011 with 234 cancer patients in Saudi Arabia,

the authors reported that 42.2% of the patients gave the “evil eye” and envy as causes of cancer.⁸ The “evil eye” as a cause of cancer was also reported by other authors in different countries.^{16,17} The beliefs regarding cancer causes and outcomes may play a detrimental role by

Table 5 - Multivariate ordinal logistic analysis to correlate the probability of getting “cancer is contagious” answer with the demographic information. Probabilities modeled are cumulated over the lower ordered values (no, occasional, yes).

Effects	Odds ratio	Lower confidence interval	Upper confidence interval	P-value
Age	1.022	0.993	1.051	0.1358
Gender: female vs. male	1.289	0.539	3.083	0.5677
Marital status: married vs. single	0.363	0.117	1.126	0.0794
Educational level: educated vs. uneducated	0.287	0.038	2.194	0.2291
Currently working: yes vs. no	9.986	1.283	77.740	0.0280
Cancer type: hematological malignancy vs. solid tumor	2.057	0.486	8.702	0.3270
Cancer cause: scientific vs. non-scientific	0.524	0.214	1.287	0.1588
Disease can be cured: occasional vs. no	1.007	0.158	6.431	0.9945
Disease can be cured: yes vs. no	1.548	0.338	7.099	0.5737
Surgery: yes vs. no	1.415	0.585	3.424	0.4412
Radiation: yes vs. no	1.225	0.508	2.955	0.6521
Chemotherapy: yes vs. no	1.295	0.462	3.636	0.6231
SCT: yes vs. no	1.825	0.203	16.418	0.5915
Cohort 2 vs. cohort 1	0.215	0.049	0.953	0.0430

SCT: stem cell transplant, vs.: versus

Table 6 - Multivariate ordinal logistic analysis to correlate the probability of getting “cancer is curable” answer with the demographic information. Probabilities modeled are cumulated over the lower ordered values (no, occasional, yes).

Effects	Odds ratio	Lower confidence interval	Upper confidence interval	P-value
Age	1.001	0.992	1.011	0.8027
Gender: female vs. male	0.988	0.722	1.350	0.9376
Marital status: married vs. single	0.804	0.587	1.102	0.1755
Educational level: educated vs. uneducated	0.808	0.517	1.264	0.3498
Currently working: yes vs. no	1.380	0.971	1.960	0.0727
Cancer type: hematological malignancy vs. solid tumor	1.010	0.661	1.541	0.9648
Cancer cause: scientific vs. non-scientific	0.621	0.423	0.913	0.0153
Disease can be cured: occasional vs. no	1.205	0.341	4.259	0.7720
Disease can be cured: yes vs. no	1.387	0.266	7.237	0.6980
Surgery: yes vs. no	0.791	0.574	1.091	0.1524
Radiation: yes vs. no	1.075	0.786	1.470	0.6514
Chemotherapy: yes vs. no	1.080	0.720	1.621	0.7083
SCT: yes vs. no	0.729	0.382	1.389	0.3359
Cohort 2 vs. cohort 1	2.303	1.586	3.344	<.0001

SCT: stem cell transplant, vs.: versus

delaying timely seeking of healthcare and appropriate medical assistance. In a systematic review with 60 studies, it was found that poor symptom knowledge, emotional barriers, fearful, and fatalistic beliefs on cancer resulted in a delay in seeking medical help.¹⁸ In another study with 4319 patients, higher fatalism was associated with greater odds of having stage 4 cancer.¹⁹

It was clear that the majority of our patients perceived that cancer was a curable disease. There was a significant change related to this perception in cohort 2, with a single-digit decrease from cohort 1. It is unclear if this was an effect of their actual cancer

condition or a preconceived perception prior to the cancer diagnosis. It is very important to dispel the myth that cancer is universally fatal in the public, as it may result in a significant delay in seeking medical assistance, in addition to heightened levels of emotional suffering. Complementary and alternative medicine was used less in cohort 2, which may be a reflection of increased awareness of the cause of cancers or a heightened awareness of some of the risks associated with alternative therapies; as a result, patients may adhere to the mainstream standard cancer treatments.

There should be a concerted effort from healthcare professionals, organizations, society, and the media to disseminate accurate information to the public regarding the causes of cancer, cancer presentation, and the realistic outcomes of cancer treatment. The education of cancer patients on their disease and potential outcomes will support them to cope with the future goals of care, whether it is palliative end-of-life care or long-term survivorship.²⁰

Study limitation. One of the limitations of our study was not using a standardized tool, such as the Cancer Awareness Measure Mythical Causes Scale.²¹ Such tools were not in existence at the initiation of the study. The tool used had been standardized in both cohorts, focusing on questions related to the perception regarding the causes and outcomes of cancer. It would have been interesting if there had been more detailed questions to identify the reasons for the change in the levels of knowledge and how that impacted the patients' behavior.

In conclusion, the study revealed the wide prevalence of misconceptions regarding the causes of cancer. Additional studies are required to identify the sources of the information and how to use these resources to correct or improve the knowledge base of the Saudi Arabian citizens. Implementing educational programs to achieve this goal in the public, as well as with cancer patients, should be a societal priority.

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