

Health information seeking behaviour in academic population and its relationship with carcinophobia: An analytical survey on Recognizing the problems and barriers to obtaining the required information resulting from Fear of cancer

Sakineh Kamyar

Graduated student, Department of Medical Library and Information Science, School of Allied Medical Sciences, Shahid Beheshti University of Medical Sciences, Tehran, Iran.

sk.kamyar@gmail.com

ORCID iD: <https://orcid.org/0000-0002-0226-9711>

Maryam Kazerani

Associate prof. Department of Medical Library and Information Science, School of Allied Medical Sciences, Shahid Beheshti University of Medical Sciences, Tehran, Iran.

corresponding author: kazerani.m@gmail.com

ORCID iD: <https://orcid.org/0000-0002-4900-3881>

Maryam Shekofteh

Associate prof. Department of Medical Library and Information Science, School of Allied Medical Sciences, Shahid Beheshti University of Medical Sciences, Tehran, Iran.

shekofteh_m@yahoo.com

ORCID iD: <https://orcid.org/0000-0002-1079-4583>

Sara Jambarsang

Associate prof. Center for Healthcare Data Modeling, Departments of Biostatistics and Epidemiology, School of public health, Shahid Sadoughi University of Medical Sciences, Yazd, Iran.

s.jambarsang@gmail.com

ORCID iD: <https://orcid.org/0000-0002-8295-7812>

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Abstract

Health information-seeking behavior is how to search, find and use disease-related information, information about health-threatening factors and activities related to health promotion. One of the issues affecting people's quality of life is chronic diseases, of which cancer can be mentioned. Cancer incidence is rising over the last years . It cannot be stated for sure that the Fear and concern about cancer which is named carcinophobia, always cause a lack of follow-up and avoidance of people seeking cancer information; however, considering different time intervals and in different cultures, the same Fear and concern as the stimulus, stimulates or forces the people to track and seek cancer information. The purpose of this analytical survey was clarifying the situation of Health information-seeking behaviour among university students both undergraduate and postgraduate as academic population during cancer outbreak. Also our aim is to determine the relationship between carcinophobia and information-seeking behavior in this population. Research findings while clarifying the situation of Health information seeking behavior in the academic population, can indicate that carcinophobia causes more information search or is a barrier to information search. The samples of this analytical survey include 243 college students who were selected by cluster-class methodology. The research tool was derived from the Cancer Information Questionnaire Levin (L_CIS). Pearson correlation test was used for the relationship between variables. The results showed that the average total score of students' fears of the disease was 27.20, which was high and the main motive for the search for cancer health information was the protection of personal hygiene(56.4%). " Knowing how to treat cancer (54.7%) and the awareness of new trends in medicine (44.9%) were in the second and third rankings of the purpose and motivation of the search for

information. Three components including "Lack of effective communication with Treatment staff (such as physicians or nurses), "Lack of mastery in searching or finding of health information resources" and "Lack of mastery in the use of print or online health information resources" in average were the most important problems and barriers to obtaining the required information resulting from Fear of cancer. With increasing Fear of cancer, people's willingness to search for information through friends and watching TV shows increased, but the severe, and morbid Fear of cancer reduced the desire of individuals to seek health information.

Keywords: Carcinophobia, Fear of Cancer, Health Information Seeking Behavior, Undergraduate Students, Postgraduate Students.

Introduction

Health information-seeking behavior (HISB) is how to search, find and use information about diseases, health-threatening factors, and the activities related to promoting Health by a person (Lambert & Loiselle, 2007; Fourie, 2009). The concepts related to HISB include the type of observed health information, the extent of the observed health information (Allen 2013; Hamzehei, Kazerani, Shekofteh & Karami, 2018), and the factors related to the source of information like the validity and authenticity of the source (Nel & Fourie 2016). Moreover, they include factors related to the messages in information sources like the clarity or ambiguity of the message and the characteristics of the searcher like understanding their own disease (Kanter, Bevan & Dorros 2019). As behavior is a psychological phenomenon affected by underlying environmental and personal factors, the patient's peripheral and personality characteristics affect his HISB. On the other hand, HISB of the patient demarcates the seeking and reception of information by him and finally affects the Health of the individual and improves his life quality (Longo, Schubert, Wright, LeMaster, Williams & Clore, 2010).

One of the most important issues affecting quality of life is chronic diseases, of which cancer can be mentioned. Cancer is one of the oldest known diseases by humans, yet recent advances in cancer science and technology have changed it from a deadly and incurable phenomenon to a chronic disease (Berrett-Abebe, Cadet, Nekhlyudov, Vitello & Maramaldi, 2019; Nelissen, Beullens, Lemal & Van den Bulck 2015b). As one of the most common and growing diseases, this disease imposes a huge amount of effort on the care systems (Micheli et al., 2003). According to WHO "Cancer is the second leading cause of death globally, accounting for an estimated 9.6 million deaths, or one in six deaths, in 2018"¹. This shows that Cancer incidence is rising over the last years. This problem during adolescence and young adulthood represent a substantial disease burden, with an estimated 1.2 million cancer cases and 400 000 cancer-related deaths occurring in 2018 (Gupta et al., 2020). So there is an emergency need for more knowledge and information about public awareness and attitudes towards cancers (Fonnes et al., 2021) via information resources like social media in libraries especially academic libraries. Social networking can be an effective method of student outreach in academic libraries if libraries provide equal coverage for all subject areas (Fong, Au, Lam & Chiu, 2020; Dickson & Holley, 2010)

On the other hand, cancer patients normally undergo some symptoms, such as pain and various physical and mental disorders (Reed, Bell, Miglioretti, Nekhlyudov, Fairman & Joseph, 2020). Immediately after diagnosis or even before, the disease may cause Fear, anxiety, and other mood disorders in a person or people related to him. They change in response to a diagnosis, relapse or improvement of the disease with a pass of time (Deng & Cassileth, 2005).

It cannot be stated that the Fear and concern about cancer always cause a lack of follow-up and avoidance of people seeking information about cancer. However, considering different time intervals and in different cultures, the same Fear and concern as the stimulus stimulates or forces the people to track and seek cancer information. Thus, the information-seeking behavior of individuals due to carcinophobia can differ at different times and in different cultures and attitudes (Mitchell, 1998)

Different studies have been done in the world related to cancer-related factors. In many of these studies, factors like age (Gray, Klein, Noyce, Sesselberg & Cantrill, 2005; Mayer et al., 2007), gender (Kelly et al., 2010; Manierre, 2015), education level, and suffering and not suffering from cancer (Rutten, Squiers & Hesse, 2006) and their effect on the level of cancer information have been examined. Early studies show that carcinophobia can deter the search and follow-up for cancer information. As Austin, Ahmad, McNally and Stewart (2002) showed, as a negative factor, carcinophobia prevents the search and discussion of cancer among women. Therefore, their level of cancer information has remained low (Austin et al., 2002). On the other hand, Nilsen et al. showed that a strong fear of cancer does not hurt cancer information-seeking behavior. It can also stimulate people to seek information about cancer, consequently increasing their information level (Nelissen, Beullens, Lemal & Van den Bulck, 2015a).

Given the authorities' warning on the possibility of cancer outbreak in developing countries (Lucas, 2008) such as Iran, the need for measures and research to reduce cancer incidence and speed up its diagnosis seems necessary.

This issue needs attention to the subscales of cancer HISB. Our queries showed that there is no study in Iran on the relationship between carcinophobia and HISB. So we aim to examine the relationship between carcinophobia and HISB among students and examine the carcinophobia and its effects that may prevent searching for cancer information or seeking more information. Our main question are:

- 1- What is the level of carcinophobi in the studied population?
- 2- What is the purpose and motivation of the studied population for HISB?
- 3- What are the problems and barriers to obtaining the required information in the studied population?
- 4- What is the information search method (active or passive)for cancer in the studied population?
- 5- What resources are used by the studied population in the active information search method for cancer?
- 6- What is the relationship between carcinophobia and HISB?

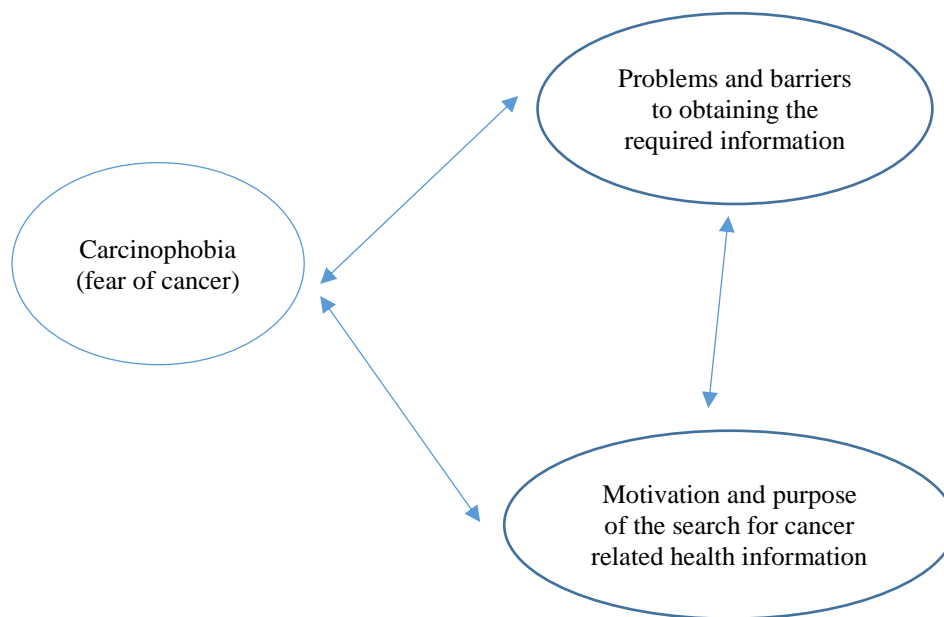


Figure 1: The relation between carcinophobia, individual motivation, and barriers to obtaining information

In other words, research findings while clarifying the situation of Health information-seeking behavior in academic population can indicate that carcinophobia causes more information search or is a barrier to information search.

Materials and Methods

This study was an analytical survey. The population was a young age group of students aged 20-30 years studying at Shahid Beheshti University, Tehran, Iran. The sample was 243 undergraduate and postgraduate students selected using the cluster-class sampling method who had consented to participate in the research.

Regarding objectives, this research collected the needed data to test the research hypothesis carcinophobia questionnaire and Leuven Cancer Information Survey (L-CIS) (Nelissen et al., 2015a). This questionnaire was a standard and cross-sectional study in Leuven (Belgium). The questionnaire is useful for the cancer population and healthy people, and its answers are sorted into 5 values for each set of questions. The questionnaire has eight questions on carcinophobia rate with 5-value responses, the sum of which determines the phobia. So The amount of data varies between 8 (minimum) and 40 (maximum). In addition, 11 questions with 5-value responses review the attendees' active and passive HISB in cancer-related health information. The questionnaire examines the level of education of each individual. The Leuven questionnaire was approved by the College of Human Sciences Ethics at the University of Leuven and had a high validity of 95% (Nelissen et al., 2015a). The validity of this tool in the studied population was approved by the experts in the health area and seeking information behavior in Iran. The reliability of this questionnaire was 0.91 for phobia and 0.93 for information-seeking behavior using Cronbach's alpha.

After receiving permission from the faculty, the questionnaires were distributed among the students in coordination with the deputy of the dormitory, the guard, and then with the co-

director of the dormitory to collect the data, and were collected the next day. After collecting the research tools, the information of each questionnaire was encoded and categorized into Excel software for statistical analysis.

The academic degrees in the present study were bachelor, master, and Ph.D. As the frequency of master's and Ph.D. degrees was low and the low frequency of these two degrees would lead to errors in the results, we combined these two sections. We compared them with bachelor level as postgraduate level education. An Independent T-test was used to examine the research question.

In tables and charts, descriptive statistics were used to estimate the mean, standard deviation, frequency, and frequency percentage. By performing Kolmogorov-Smirnov test (KS) test, the normality of the data was proved. The Pearson correlation coefficient was used to determine the relationships between the variables. Fischer Z test was used to compare the correlation coefficients.

Results

The demographic characteristics of the population

Table 1

Age frequency distribution in the studied population

Age	Frequency	Mean	sd
	243	23.58	±2.56

Table 1 shows that the mean age and standard deviation of the study participants were 23.85 and ±2.56, respectively.

Table 2

Gender frequency distribution in the studied population

Sex	Frequency	Percentage
Female	126	51.9
Male	117	48.1
Total	243	100

Table 2 shows that 51.9% of the participants were females, and 48.1% were males

Table 3

Grade frequency distribution in the studied population

Grade	Frequency	Percentage
Bachelor	159	65.4
Master	66	27.2
Phd	18	7.4
Total	243	100

Table 3 shows that the students who were studying in bachelor grade, had more participants in the study (65.4%)

Table 4

"Cancer History" frequency distribution in the studied population

Cancer History	Frequency	Percentage
Yes	79	32.5
No	164	67.5
Total	243	100

Table 4 shows that 32.5% of the participants had a family cancer history, and 67.5% did not.

Table 5

"Interest in searching for cancer information" frequency distribution in the studied population

Interest in searching for cancer information	Frequency	Percentage
Yes	181	74.5
No	62	25.5
Total	243	100

Table 5 shows that 74.5% of the participants were interested in searching for cancer information, and 25.5% were not.

Table 6

Mean and score of carcinophobia in the studied population

Index	Min.	Max.	Mean	SD
Carcinophobia	10	36	27.20	6.18

As it can be seen in Table (6), the minimum and maximum scores for carcinophobia was 10 and 36, respectively. The mean and standard deviations were 27.20 and ± 6.18 , respectively.

Table 7

Motivation and purpose of the search for cancer-related health information in the studied population

No.	Purpose and motivation	Strongly Disagree N (%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly Agree N (%)	Total N (%)
1.	Data collection	38(15.6)	73(30)	22(9.1)	60(24.7)	50(20.6)	243(100)
2.	Awareness of new medical trends on cancer	0	46(18.9)	10(4.1)	79(32.5)	108(44.5)	243(100)
3.	Gaining ability to describe cancer	52(21.4)	44(18.1)	65(26.7)	72(29.6)	10(4.1)	243(100)
4.	Gaining information before or after illness	6(2.5)	58(23.9)	88(36.2)	77(37.1)	14(5.8)	243(100)
5.	Gaining others' idea on cancer	68(28)	71(29.2)	57(23.5)	47(19.3)	0	243(100)
6.	Getting medical	11(4.5)	55(22.6)	66(27.2)	83(34.2)	28(11.5)	243(100)

No.	Purpose and motivation	Strongly Disagree N (%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly Agree N (%)	Total N (%)
	counseling						
7.	Deciding to meet with a physician	17(7)	75(30.9)	62(25.5)	64(26.3)	25(10.3)	243(100)
8.	Knowing how to treat cancer	11(4.5)	28(11.5)	19(7.8)	133(54.7)	52(21.4)	243(100)
9.	Acquiring information anonymously	63(25.9)	87(35.8)	67(27.6)	22(9.1)	4(1.6)	243(100)
10.	Managing health costs	6(2.5)	29(11.9)	53(21.8)	106(43.6)	49(20.2)	243(100)
11.	Personal health protection	0	16(6.6)	20(8.2)	137(56.4)	70(28.8)	243(100)
12.	Improving life quality	9(3.7)	28(11.5)	14(5.8)	90(37)	102(42)	243(100)

As it is shown in table (7), the protection of personal Health, with 56.4% in favorable response, was the highest percentage of motivation to seek health information in the studied population. After that, " Knowing how to treat cancer (54.7%) in the favorable response, and the awareness of new trends in medicine (44.0%) in the very favorable response was in the second and third rankings of the search for information.

Table 8

Problems and barriers to obtaining the required information resulting from Fear of cancer

No.	Problems and barriers	Strongly Disagree N (%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly Agree N (%)	Total N (%)
1	Language differences or Lack of translation of useful resources	27(11,1)	100(41,2)	71(29,2)	39(16)	6(2,5)	243(100)
2	Lack of access to print or online health information resources	8(3.3)	138(56.8)	69(28.4)	28(11.5)	0	243(100)
3	High costs of access to health information resources	28(11.5)	161(66.3)	54(22.2)	0	0	243(100)
4	Lack of mastery in the use of print or online health information resources	0	7(2.9)	81(33.3)	145(59.7)	10(4.1)	243(100)
5	Lack of mastery in searching or finding of health information resources	0	0	62(25.5)	148(60.9)	33(13.6)	243(100)
6	Lack of effective	0	0	4(1.6)	112(46.1)	127(52.3)	243(100)

No.	Problems and barriers	Strongly Disagree N (%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly Agree N (%)	Total N (%)
	communication with Treatment staff (such as physicians or nurses) to receive health information						

As it is shown in table (8), on average, three components, including "Lack of effective communication with Treatment staff (such as physicians or nurses), "Lack of mastery in searching or finding health information resources," and "Lack of mastery in the use of print or online health information resources were the most important problems and barriers to obtaining the required information resulting from Fear of cancer.

Table 9

Correlation matrix between carcinophobia and resources used for HISB

Variable	Type		carcinophobia
Information Resources in Active HISB	Friends	R	0.95**
		P	0.001
	Educational website	R	0.11
		P	0.26
	Social Networks	R	-0.95**
		P	0.001
	TV: Informative show	R	-0.44**
		P	0.001
	TV: Medical programs	R	0.37**
		P	0.001
Information Resources in Passive HISB	Friends	R	0.66**
		P	0.001
	Family	R	0.34**
		P	0.004
	Internet: Educational Website	R	-0.24**
		P	0.007
	Internet: Public Sector	R	-0.07
		P	0.39
TV: Informative show	R	0.06	
	P	.43	
TV: Medical programs	R	-0.58**	
	P	0.001	

**P<0.001

As it is seen in Table (9), there is a significant positive relationship between carcinophobia and using Information Resources in Active HISB, including friends and television (medical programs). In contrast, there is a significant negative relationship between carcinophobia and the using social networking and television programs in Active HISB (P<0.05). There is a significant positive correlation between carcinophobia and using Information Resources in

Passive HISB, including friends and family. There is a significant negative relationship between the Internet, educational websites, and television programs in this type of HISB($P < 0.05$).

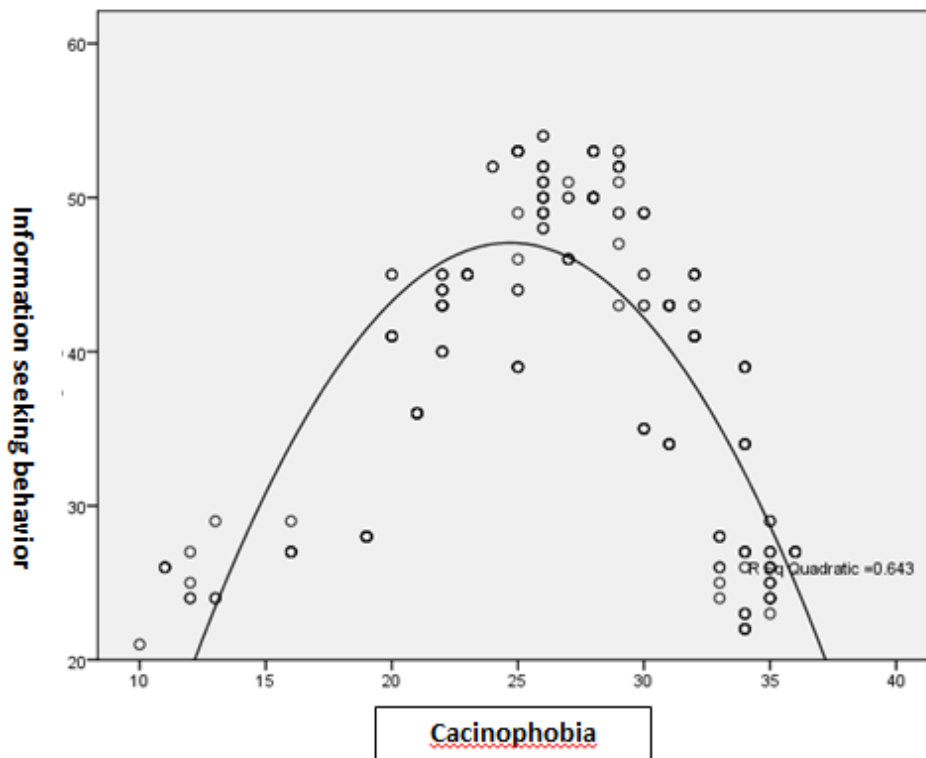


Chart 1: Dispersion of phobia and cancer information seeking behavior

As it is displayed in dispersion chart 1, up to a moderate level, phobia motivates information-seeking behavior about cancer. Still, the score of information-seeking behavior decreases considerably with an increase in phobia.¹

Table 10

The results of one-way variance analysis on carcinophobia in different educational levels

	Education	Frequency	Mean	SD	t	P
Carcinophobia	Bachelor	159	28.05	4.81	2.58	0.011
	Postgraduate studies (master and PhD)	84	25.06	7.96		

As it is depicted in Table 10, there is a significant difference between the carcinophobia with bachelor's and postgraduate education levels (master's and PhD) ($t = 2.58, p = 0.011$).

Table 11

The results of independent T analysis in carcinophobia and family history of cancer

	History	Frequency	Mean	SD	t	P
Carcinophobia	Yes	79	28.88	5.47	3.14	0.002
	No	164	26.40	6.35		

As it is seen in Table 11, there is a significant difference between the history of having and not having cancer in the family with carcinophobia ($P = 0.002$, $T = 3.14$); among the people with cancer history in the family, carcinophobia is more than that in the people with no history of cancer.

Discussion

Humans turn to HISB for two reasons: to address specific health concerns (for themselves or a member of their social circle) and to research subjects for school health classes. (Gray et al., 2005) They are worried about their health issues, families, and friends. They want to know how to preserve their Health, treat diseases, and understand how to treat the disease and its conditions. Thus, carcinophobia can be important in motivating people to seek health information (Emanuel et al., 2015). The study aimed to determine the relationship between carcinophobia and HISB among the students as an academic population. The results showed that the average carcinophobia score of students was 27.20. This score showed that most of the studied students feared cancer at a high level. In a study by Nelissen et al. (2015a), about 19% of participants had a low phobia, 34% had a moderate and about 47% high phobia (Nelissen et al., 2015a). Hence, the carcinophobia in the population above seemed lower than in those who participated in the current study. Another factor of this difference can cite the sociocultural differences between the populations (Iran and Belgium) and the age difference of the participants. The participants in the current study were 20 to 30 years old, but in Nielsen et al. were from 16 to 88 years old. Also, the difference in the health and education system in the two countries can be considered as another factor; as a European and advanced country, Belgium has a stronger educational and Health system than Iran, and education and health services are free in this country. Furthermore, it can be more successful than Iran in treating cancer due to the better technology and more advanced health facilities. This matter can reduce carcinophobia of people in this community.

Protection of Personal Health (56.4%), familiarity with the treatment of cancer (54.7%), and familiarity with new medical trends (44.5%), respectively, were the main goals and motivations of the students for the search of health information about cancer. The participants showed that protecting personal Health and familiarity with the procedure of cancer treatment could stimulate seeking health information about cancer more than other factors. Given the increasing trends of using social networking services in academic libraries (Fong et al., 2020), If Academic libraries have more educational programs in the field of Health and health protection via social medias; It can be very helpful. In this study, a healthy lifestyle (personal Health) and familiarity with the disease and its treatment procedure were among the important factors stimulating women's search for health information. Hence, the results of Nikbakht Nasrabadi, Sabzevari and Negahban Bonabi (2015) are in line with the current results. However, they were not in line regarding the order of priority. It may be for difference in participants in the study, as Nikbakht Nasrabadi et al. (2015) conducted their study only in a wider age group of women. However, the current study was conducted with the participation of women and men and only among students aged 20-30, which could affect the prioritization.

"Lack of effective communication with Treatment staff (such as physicians or nurses), "Lack of mastery in searching or finding of health information resources," and "Lack of mastery in the use of print or online health information resources were the most important problems and barriers to obtaining the required information resulting from Fear of cancer. Almost all studies

in this survey have cited similar barriers to obtaining the required information, and the only difference is in the priority of these problems, which can be related to differences in individuals and the location and culture of people in the community.

In a general division, the HISB can be divided into two active and passive forms. In an active method, people knowingly and deliberately seek health information among different information resources to gain information about the subject in question and thus obtain information about the considered subject. However, in a passive method, the person without any intention is exposed to health information in various sources (Fourie, 2009), increasing his information about a specific topic. The results indicated that from among 243 participants in this study, 122 individuals (50.2%), actively seek health information on cancer. In addition, 242 (99.6%) participants stated that they were inactively exposed to cancer information and had received it on cancer inactively. In studies within Iran, few researchers have examined these two methods of seeking information. Still, in foreign studies, Nelissen et al. (2015a) have examined these methods, showing that both methods of seeking information have increased health information among the participants.

Conclusion

The results indicated a significant positive relationship between carcinophobia and using Information Resources in Active HISB, including friends and medical programs on television. In other words, the greater the carcinophobia of people was, the more interest they showed in seeking information from friends and medical TV programs. Nevertheless, there was a significant negative correlation between carcinophobia and using social networks and television programs in this type of HIBS ($P < 0.05$). This means that people's tendency to use social networks and informative television programs to seek health information on cancer is reduced with increased carcinophobia. There was a significant positive relationship between carcinophobia and using Information Resources in Passive HISB. However, there was a significant negative relationship between the Internet, educational websites, and medical programs on television ($P < 0.05$) in this type of HISB. In other words, with an increase in carcinophobia in Passive HISB, gaining information through friends and family increased, while gaining it through the educational website and the medical television program decreased.

According to the results, fears to an average level can motivate information-seeking behavior about cancer. In other words, with the increase in carcinophobia, people's desire to seek health information about cancer increases. This increase continues until the Fear reaches a specific extent. However, after that, with an increase in carcinophobia of people and the Fear reaching a high level, people's willingness to seek health information about cancer reduced. In the study by Whitaker, Cromme, Winstanley, Renzi and Wardle (2016), it was stated that low Fear, known as a concern, increases seeking cancer information but high phobia has stopped seeking cancer information, which was consistent with the current study (Whitaker et al., 2016). The results were also in line with the studies by (Nelissen et al., 2015a) and (Hay, Buckley, & Ostroff, 2005), but inconsistent with the studies by (Dubayova et al., 2010) and (Moser, McCaul, Peters, Nelson & Marcus, 2007). The main reason for the difference of these results is the research method. They did not examine phobia at different levels and only examined the relationship between the presence and absence of phobia and HISB.

Another point from the study was a significant relationship between carcinophobia and academic degree: the degree of Fear at the bachelor's level was higher than that of the

postgraduate level. The relationship between carcinophobia and educational level has been overlooked, and studies have been limited in this area. In addition, the relationship between carcinophobia and gender showed a significant relationship between these two components and the carcinophobia among women in the studied population was significantly higher than that of men. The results of this section of the study were in line with the results of (Nelissen et al., 2015a), (Ackerson & Preston, 2009), and (Austin et al., 2002). Women are more concerned about their Health than men, given their more sensitivities, and this concern increases the carcinophobia among females.

The results indicated that carcinophobia is higher among people with such a history. The results of this study section were in line with (Nelissen et al., 2015a) and (Taha, Al-Qutob, Nyström, Wahlström & Berggren, 2012). A history of cancer in the family or close people and witnessing the difficulties these people go through during the illness and to cope with it makes people with a family history of cancer more likely to worry about this diseases compared to others, so the level of carcinophobia was higher than other people in the population.

Since there is a widespread opinion that cancer inevitably leads to a painful death, This may contribute to society's carcinophobia and denial with subsequent frequent delays in seeking medical attention and treatment for suspected cancer (Reich, Gaudron & Penel, 2009). We found in this study that having Conventional Fear of cancer led to optimal information-seeking behavior; however, morbid Fear of cancer decreased the tendency of information-seeking. As it said, Fear of cancer was high among students, especially undergraduates, so adopting appropriate publicity policies is possible to influence HISB and improve it desirably.

Generally, Due to rising Cancer incidence among young people (Gupta et al., 2020) , the effect of carcinophobia on HISB and the increasing use of social networks in academic libraries (Fong et al., 2020; Dickson & Holley, 2010), This is an important issue to Pay attention to the role and value of academic libraries in providing educational programs in the field of Health.

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Endnotes

1. https://www.who.int/health-topics/cancer#tab=tab_1
2. The regression model with the second power of phobia as an explanatory variable was used to express this correlation.

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