

# Cancer Awareness and Barriers to Seeking Medical Help Among Syrian Refugees in Jordan: a Baseline Study

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**Abstract** Refugees in Jordan have an increased burden of cancer due to hard conditions and low income. An increase in awareness of the early signs of cancer could prompt early diagnosis. The current study aims to explore the level of cancer knowledge and barriers to seeking care among Syrian refugees in Jordan. A descriptive cross-sectional survey design was used. Two hundred and forty-one Syrian refugees living in the north of Jordan completed the Cancer Awareness Measure. The mean age was 27.9 (SD 9.1) years, ranging from 18 to 47 years. More than half (56%) of the participants were female. Participants were able to recognize a low number of symptoms (mean 4.4, SD 2.3) and risk factors (4.7 (out of 11), SD 1.9). The most commonly reported barrier was having no medical insurance (83.4%). Refugees' knowledge of symptoms and risk factors was generally unsatisfactory. Barriers to seeking medical care were prevalent. Much work is needed to overcome barriers and enhance knowledge that can hinder early diagnosis and treatment.

**Keywords** Refugees · Cancer · Awareness · Jordan · Health · Adult

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## Introduction

Cancer constitutes a major health problem worldwide, with eight million cancer-related deaths occurring each year [6]. Figures for incidence and prevalence are showing an increase in the size of this problem. The incidence of cancer is higher in high-income countries than in middle- to low-income countries; however, most deaths occur without treatment or palliative care in the latter case [11]. In Arab countries, cancer is a major health problem because of changing lifestyle, obesity and diabetes [19]. There is no comprehensive scientific data on the incidence, prevalence, cure and death rate for cancer within the Arab world [13, 19]. Although some countries have cancer registries, others, including Syria, have no such infrastructure [13, 16, 19]. Cancer detection, treatment and patient support therefore vary considerably within the Arab world, but can be described as scattered and poorly organized [13, 19]. However, it is estimated that some 360,000 new cancer cases could be detected by 2020 [13]. Unfortunately, little information about cancer and its burden in Syria has been published. The World Health Organization (WHO) reported that 8% of non-communicable disease-related deaths were attributed to cancer in 2011 (at the beginning of the war) and this figure increased to 11% in 2014 [16], although the actual figure might be higher given the uncertainties resulting from the war. As in most developing or lower income, Syria was already struggling with the financial burden of cancer treatment, having no well-established early detection and treatment system and even no policy at the national level. The cost of cancer treatment was \$17.4 million in Jordan and \$34.6 million in Syria [13], and it is expected that the state of cancer detection and treatment will deteriorate with the war in Syria.

Combinations of genetic and environmental factors (risk factors) like sedentary lifestyle, tobacco and alcohol consumption, pollution and viral infections are responsible for the occurrence of cancer [26, 30]. Obviating these risk factors and early

diagnosis can significantly decrease the incidence [22]. For instance, one study showed that cancer-related deaths decreased by 17% with early diagnosis [8]. Suffering, pain, mortality and significant loss to individuals, in addition to increased workload and cost to the healthcare system, are the major consequences [3].

Refugees in general have an increased burden of cancer due to hard conditions and low income [4]. Hard conditions include but are not limited to fear of the unknown, instability when moving to a new country, safety concerns and settlement difficulties [4, 25]. In addition, Syrian refugees fled from what was already classified as a low-income country to Jordan, which itself has complicated economic problems which may exaggerate the financial dilemma [25]. Added to this is insufficient international funding to cover healthcare costs, as the number of refugees increases daily [4]. Overall, the burden of cancer to the host countries (low and middle income) is not fully understood. Furthermore, there are more deaths from cancer among refugees than permanent citizens [23]. Refugees also negatively affect the demographics and healthcare system of the host country, which in turn may increase the burden of disease in all its citizens [23]. Syrian refugees in Jordan are no exception, especially as Jordan itself is facing many health and economic challenges. There are no statistics on the incidence of cancer in Syria or among Syrian refugees. However, one study that examined refugees in Jordan and Syria from 2009 to 2012 reported that the number of documented cases had increased because the number of refugees increased as more people fled Syria [7].

An increase in awareness of the early signs of cancer could prompt early diagnosis [24]. At the same time, preventing risk factors through adopting a healthy lifestyle and environmental modification might also prevent cancer [22]. In this context, a number of studies have explored the level of awareness of signs of cancer. For instance, in a British study, it was found that the knowledge level of cancer signs was lower in individuals in lower socio-economic groups. Difficulty in making a doctor's appointment, fear of wasting the doctor's time, and fear of what might be found were all barriers to seeking help [18]. A different study conducted in Australia had similar results: using a cross-sectional survey to measure awareness of the level of cancer symptoms, it found that only 19% of the 366 subjects were aware of the symptoms [10]. In the Arab region, a Saudi study was conducted to examine knowledge of breast cancer, practice and screening and the barriers among women in primary healthcare. Findings revealed a poor knowledge of the warning signs of breast cancer. The most frequently reported barrier to screening was believing that mammography is painful [2]. In Jordan, a large-scale survey (3196 participants) was conducted to explore cancer knowledge and beliefs in the Jordanian population, finding knowledge gaps and inappropriate practices. The study considered these gaps as barriers which, if corrected, could facilitate care [1].

A number of studies have also explored knowledge and barriers for cancer in immigrants and refugees in high-income

countries. One study conducted in Canada on Arab immigrants found a lack of knowledge regarding cancer symptoms. Social influence was the greatest barrier to seeking advice [3]. Other studies conducted in the USA among refugees also reported lack of knowledge and cultural and language barriers to seeking help [20, 21]. In Jordan, one study was found that explored health-seeking behaviour among Syrian refugees in different types of illness including cancer, finding strong health-seeking behaviour. About 86.1% of the refugees had sought medical help the last time it was needed, but there was no information specifically about cancer patients [9]. In a different publication on cancer in Syrian refugees in Jordan between 2009 and 2012, the United Nations High Commission for Refugees (UNHCR) reported that only 246 out of 511 Syrian refugees applying for cancer treatment were approved, because of a shortage of funds [25].

The literature review found no studies that directly examined the knowledge and barriers to seeking care among Syrian refugees in Jordan. Although studies conducted in non-Arabic speaking countries concluded that differences in culture and language could be a barrier, the situation for the Syrian refugees in Jordan is different, as both countries are part of the Arab region called Levant, which also includes Palestine and Lebanon. Despite differences in their political systems and religious sects, these countries have the same language and ethno-religious background [15], so the aforementioned factors should not be valid in this case.

To summarize, Jordan has the largest population of refugees per capita in the world, mostly Syrians [12]. Understanding the level of knowledge about cancer in this group, and the barriers to seeking care in a serious illness like cancer, is vital to reduce the burden on the Jordanian health system and improve the refugees' health status. The current study therefore explores the level of cancer knowledge and the barriers to seeking care among Syrian refugees in Jordan.

## Aims

This study aims to answer the following research questions:

1. Are Syrian refugees aware of the warning signs of cancer?
2. Are Syrian refugees aware of cancer risk factors?
3. What are the perceived barriers by Syrian refugees to seeking medical help?

## Methods

### Design

A descriptive cross-sectional survey design was used to answer these research questions.

## Sample and Setting

The subjects are Syrian refugees living in the northern cities of Jordan. Participants must be older than 18, not living in a camp, able to read and write, physically able to complete the questionnaire and willing to take part in the study. Otherwise, participants were excluded. Participants were recruited from different places: three public primary healthcare centres (120 participants; 40 from each one), two private healthcare centres (40 participants; 20 from each one) and four maternity and childcare centres (81 participants, with around 20 from each).

## Instrument

The Cancer Awareness Measure (CAM) [5] was used, as it is the only known validated tool in this field [27]. It has good internal reliability (Cronbach's  $\alpha = 0.77$ ) and good test-retest reliability ( $r = 0.81$ ). CAM asks about awareness of cancer symptoms (one open question and ten items), anticipated delay (one closed question) and barriers to seeking help (ten closed questions). In regard to awareness, the sub-scale starts with an open question asking the subject to list whatever he/she knows of cancer warning signs; this is followed by ten items with (yes/no) answers. Anticipated delay is evaluated by a closed question with two categories: low (< 2 weeks) and high (> 2 weeks). The remaining 11 items are about barriers to seeking help (yes/no), including four emotional, three practical and three service barriers. We added, "no medical insurance to cover the cost" under the service barriers sub-scale. Information about participants' demographic characteristics, such as sex, age, marital status, economic status and education was also collected. Permission to use the tool was obtained, and it was translated into Arabic using the back-translation technique: first, the research team translated the English version into Arabic, which was given to an independent translator to translate it back from Arabic to English, and compared with the original version. Some errors were corrected to maintain the meaning. The Arabic version of the tool was then reviewed by two Ph.D. holders for its content and its suitability to the Arabic context. They suggested minor amendments related to language; these were implemented and corrected accordingly. Finally, the research team piloted the study on a group of 20 Syrian refugees to test the tool for its readability and clarity. Participants considered that the tool was clear and easy to read and comprehend; no other issues were reported.

## Procedure

The researchers first sought ethical approval to embark on the study from the Al Al-Bayt University Ethics Committee. Then, research assistants visited the local primary healthcare centres (public and private) and maternity and childcare centres. The approval to conduct the study was shown to the

managers of these centres. If subjects agreed to be included in the study, a brief presentation of the purpose, procedure and requirements was given in the waiting areas. All participants who agreed to participate were informed that filling in the questionnaire would be considered as an implicit consent form, and they completed the questionnaire in the presence of a research assistant to provide help if needed. Participants were told that they had the right to withdraw at any time.

## Data Analysis

Data was entered into SPSS (Release 21). The sample descriptive statistics were estimated using means, median, frequency, percentages across the entire sample and for the key sub-groups. The statistical differences between two variables (yes/no) were analysed using two-group tests such as the Mann-Whitney *U* test.

## Results

### Sample Demographics

In this study, 241 Syrian refugees living in the north of Jordan completed the study questionnaire. The mean age was 27.9 (SD 9.1) years, ranging from 18 to 47 years. More than half (56%) of the participants were female and married (51.9%); see Table 1. Most (56.1%) did not have a first relative with cancer. Less than half (45.2%) of the participants were medically insured, and 75.1% considered they would seek medical care within 2 weeks if they noticed any alarming symptom.

### Awareness of Symptoms

Participants were first asked to recall whatever they knew of cancer symptoms (recall), and then asked to identify nine common symptoms that may precede the detection and diagnosis of cancer (recognition). Participants (25.7%) were able to recall that "unexplained lump or swelling" is one of the alarming signs. However, only 12.4% were able to correctly recall "unexplained weight loss" as one of the early symptoms. All other symptoms were correctly recalled by less than 8.3% of the sample; see Table 2. In contrast, participants were able to recognize a small number of symptoms (mean 4.4, SD 2.3). The most commonly known symptoms were as follows: having a mass or a swelling (79.3%), unexplained weight loss (55.6%), persistent cough or hoarseness (51%) and unexplained bleeding (50.2); all other symptoms listed in the questionnaire were correctly recognized by less than 48.5% of the participants (see Table 2).

**Table 1** Sample demographics

Variable	Frequency (%)
Gender	
Male	106 (44.0)
Female	135 (56.0)
Marital status	
Married	125 (51.9)
Not married	116 (57.1)
Working status	
Working	40 (16.6)
Not working	201 (83.4)
Education level	
Low education ( $\leq$ secondary school)	177 (73.4)
High education ( $\geq$ diploma)	64 (26.6)
Family monthly income (US\$)	
Low ( $<$ 845\$)	210 (87.3)
High ( $\geq$ 845\$)	31 (12.7)
Having first degree relative with cancer	
Yes	84 (34.9)
No	157 (65.1)

### Risk Factors

Table 3 details participants' knowledge and awareness of cancer-related risk factors. The mean number of total risk factors recognized was low, at 4.7 (out of 11), SD 1.9. Most knew that smoking (78.4%) and second-hand smoking are major risks of cancer (see Table 3), and 75.1% identified drinking alcohol. However, only 16.6% of participants identified a sedentary lifestyle as a risk factor, and 24.1% were not aware that low vegetable and fruit intake increases the risk. The percentage of refugees who correctly identified other listed risk factors ranged from 22.8 to 48.5% (see Table 3).

**Table 2** Frequency and percentage of participants' knowledge of warning cancer symptoms

Symptom	Recognition		Recall	
	Yes		Yes	
	Frequency	%	Frequency	%
1. Unexplained lump or swelling	191	79.3	62	25.7
2. Persistent unexplained pain	100	41.5	20	8.3
3. Unexplained bleeding	121	50.2	15	6.2
4. Persistent cough or hoarseness	123	51.0	19	7.9
5. Persistent change in bowel or bladder habits	117	48.5	2	0.8
6. Persistent difficulty swallowing	91	37.8	3	1.2
7. Change in the appearance of a mole	87	36.1	1	0.4
8. Sore that does not heal	98	40.7	1	0.4
9. Unexplained weight loss	134	55.6	30	12.4

### Barriers to Seeking Prompt Medical Care

The mean of the total number of barriers reported by the Syrian refugees was 5.2 (SD 2.3). The most commonly reported barriers include the following: having no medical insurance (83.4%), being worried about what might be found (77.2%), being embarrassed (61.4%) and scared (55.6%) and difficulty in getting a medical appointment (52.3%); see Table 4. Most of the barriers were emotional in nature (mean = 2.3, SD 1.0); see Table 4.

### Bivariate Analysis

The total number of recognized symptoms was compared with participants' demographics using the Mann-Whitney  $U$  test. The results show that there was a significant difference in the number of symptoms recognized by males (Mdn = 5) and by females (Mdn = 5),  $U = 4938.00$ ,  $z = -4.169$ ,  $p = <.001$ . In addition, participants who reported seeking medical care within 2 weeks (Mdn = 4) tended to recognize a higher number of symptoms than those who might wait more than 2 weeks (Mdn = 3),  $U = 3006.00$ ,  $z = -3.313$ ,  $p = .001$ .

In regard to the total number of perceived barriers to seeking medical care, highly educated participants (Mdn = 7) reported a significantly higher number of barriers than the poorly educated (Mdn = 5),  $U = 3356.00$ ,  $z = -5.147$ ,  $p = <.001$ . Also, more males (Mdn = 6) faced barriers than female participants (Mdn = 5),  $U = 4938.00$ ,  $z = -3.313$ ,  $p = <.001$ ; and a significantly higher median number of barriers were reported by participants who might delay seeing a doctor for 2 weeks or more (Mdn = 6) than those who reported seeking care within 2 weeks (Mdn = 4),  $U = 2683.00$ ,  $z = -4.108$ ,  $p = <.001$ . Participants who tended to delay seeking medical care also knew a significantly higher median number of risk factors (Mdn = 3) than did early medical care seekers (Mdn = 6),  $U = 4938.00$ ,  $z = -3.313$ ,  $p = <.001$ . Finally, no significant

**Table 3** Frequency and percentage of participants’ knowledge of cancer risk factors

Risk factor	Yes	
	Frequency	%
1. Smoking any cigarettes at all	189	78.4
2. Exposure to another person’s cigarette smoke	182	75.5
3. Drinking more than 1 unit of alcohol a day	181	75.1
4. Eating less than 5 portions of fruit and vegetables a day	58	24.1
5. Eating red or processed meat once a day or more	55	22.8
6. Being overweight (BMI over 25)	75	31.1
7. Getting sunburnt more than once as a child	109	45.1
8. Being over 70 years’ old	57	23.7
9. Having a close relative with cancer	117	48.5
10. Infection with HPV (human papillomavirus)	88	36.5
11. Doing less than 30 mins of moderate physical activity 5 times a week	40	16.6

difference in the number of symptoms, number of barriers or number of risk factors was noted in relation to other demographics ( $p > .05$ ).

**Discussion**

This study is the first of its kind to explore knowledge and barriers to seeking medical care among Syrian refugees, not just in Jordan, but worldwide. The use of CAM enabled the collection of reliable data, congruent with the study aims, because it contained data about knowledge and barriers to seeking care for cancer. Adding demographic data and health insurance to CAM gave a base to compare additional variables, i.e. gender, income, education, employment, with the

knowledge and barrier components of the tool. The demographic part also asked if the participant had a first-degree relative with cancer, and 34.9% answered yes. This may perhaps reveal a high incidence of cancer among Syrian refugees or Syrians in general.

Awareness of cancer symptoms was generally low for the study sample, and as expected, it was lower for the recall question than for the recognition questions. In the recall question, only 25.7% were able to mention the presence of unexplained lumps as a sign of cancer, and other signs were very poorly recalled (less than 12.4%). Only four symptoms were recognized by half or more of the sample, namely unexplained lump, unexplained bleeding, persistent cough and unexplained weight loss. These findings could be explained by the low educational level of the sample and by low income, as only 26.6% of participants had received higher education and 87.3% had a low monthly income. Reportedly, low income and educational level are associated with decreased cancer awareness [14]. As men in the sample had a higher educational level, this also explains why men recognized more cancer symptoms than females (38% are highly educated compared to 20% of the women). Awareness of cancer symptoms in the current research is not only considered low, but one of the lowest when compared with other studies conducted in the Arab region [17], and among minorities in Western countries using the same methodology [29].

Knowledge about risk factors for cancer was no better than the sample’s awareness of cancer symptoms, participants in general demonstrating only a low knowledge level for cancer risk factors. Only smoking, second-hand smoking and drinking alcohol were well-recognized risk factors, with more than 75% of the participants recognizing them. The remaining eight risk factors from Table 3 were rarely recognized. Other risk factors, such as exercise, age, eating insufficient fruit and vegetables, were lowest. These findings are consistent with the literature, as other studies reported that smoking and

**Table 4** Perceived barriers to seeking medical care

	Mean (SD)	Yes	
		Frequency	%
Emotional barriers	2.3 (1.0)		
Worried about what doctor might find		186	77.2
Too scared		134	55.6
Too embarrassed		148	61.4
Not confident to talk about symptoms		74	30.7
Practical barriers	1.3(1.1)		
Too busy		98	40.7
Other things to worry about		84	34.9
Difficult to arrange transport		117	48.5
Service barriers	1.7 (1.1)		
Difficult to make appointment		126	52.3
Worried about wasting doctor’s time		50	20.7
Difficult to talk to doctor		69	28.6
No medical insurance to cover the cost		201	83.4

second-hand smoking were the most recognized risk factors, while eating less fruit and vegetables was least recognized [3, 29]. In this context, awareness of cancer symptoms and risk factors is not an isolated event. Participants who reported seeking help within 2 weeks had significantly higher awareness of symptoms and reported knowing a higher number of risk factors; in turn, this will be reflected as better prevention and earlier diagnosis, and consequently, better prognosis.

Barriers to seeking prompt medical care are consistent with the anticipated delay in seeking help. The most frequent of the reported barriers in this study was lack of insurance to cover the cost of medical care. This is not surprising, as most of the Syrian refugees had a low income (87.3%) and were not employed (83.4%), so limited funds meant that they could not afford medical insurance [7]. At the beginning of the war, the total cost of medical care was met by UNHCR and other agencies [28], supporting access to various healthcare services including but not limited to vaccination, antenatal care and care in cases of chronic disease [28]. However, with the increased number of refugees and cuts in the international funding, the refugees are now asked to contribute more to the cost of healthcare services. To be eligible for the partially funded services, refugees must be registered on the UNHCR database and Jordanian registries, which might be perceived as a security threat and therefore limit their accessibility to healthcare services. UNHCR's latest survey to assess Syrian refugees' accessibility to healthcare services in Jordan reported that 57% of the sample were unable to pay the cost of the medical care [28]. The UNHCR website warned that cancer patients among Syrian refugees went untreated because of the unavailability of financial support. This might complicate and reduce the well-being of Syrian refugees in general and cancer patients in particular.

Other widely reported barriers were emotional in nature, such as worry about what the doctor would say and being too scared or embarrassed. Being worried or scared could be attributed to lack of knowledge regarding cancer symptoms; participants might believe that anything could be malignant, while in fact it was not. Being embarrassed is attributed to the conservative nature of the refugees, women especially worrying about being seen by a physician of the opposite sex. Previous research similarly reported being scared or worried and embarrassed as barriers; however, being afraid of wasting the doctor's time or difficulty in talking to the doctor, widely reported in the literature, was not strongly represented here [29]. This could be due to cultural variations with the host community in previous studies, while Jordanians and Syrians have similar cultural backgrounds [15].

### Limitations

The current study targeted refugees living in the northern part of Jordan. In other circumstances, this might limit the

generalizability of the study, but as the largest proportion of refugees are living in the north, due to its proximity to the Syrian border, this is less relevant. Knowledge of risk factors, cancer symptoms and barriers to seeking care are not the only factors in cancer prevention, because some types of cancer are symptomatic and not all risk factors are well known. The availability of screening services and health promotion programmes is also important and must be addressed in future studies. Further, age is biased towards the younger population (mean = 27); one reason for this might be the recruitment from maternity and childcare clinics. Another explanation could be that the refugee population tends to be young in general. Finally, we acknowledge that the results of this study might be limited by the small sample size due to practical issues in recruiting the participants. Prospective researchers are advised to use a larger sample size to enhance the generalizability of the findings.

### Conclusion

This study is the first to explore knowledge of and barriers to cancer treatment for Syrian refugees in Jordan. Their knowledge of symptoms and risk factors was generally unsatisfactory. Barriers to seeking medical care, especially financial and emotional ones, were prevalent. Much work is needed to overcome barriers and enhance knowledge, to encourage early diagnosis and treatment.

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