

# The Awareness of Keratoconus among General Population in Saudi Arabia

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# Abstract

Introduction: Keratoconus (KCN) is one of the degenerative corneal disorders, which causes impairment in normal visual acuity with a higher prevalence in Saudi Arabia. The study aimed to assess the awareness and knowledge regarding KCN, its risk factors, and management among the Saudi population. Materials and Methods: A survey was conducted using a pre-tested and validated questionnaire distributed through online platforms. A mixture of convenience and snowball sampling techniques was adopted for sample collection. Our analysis included a final sample size of 837 participant responses. The questionnaire had items related to sociodemographic characteristics (5 items), knowledge (10 items), and source of information (1 item). The mean knowledge scores were calculated and categorized (good, fair, and poor) to assess each participant's knowledge. Pearson's chi-square test was used to determine the statistical association between categorical variables. **Results:** The mean knowledge score was found to be  $4.12 \pm 2.6$ , and 67.5% of the participants showed "poor" scores. There was no statistically significant association of knowledge scores observed with any of the sociodemographic details. It was agreed by 76% and 42.5% that genetic predisposition and chronic eye inflammation could predispose to KCN. Only 38.1% (n = 157) agreed that KCN could be treated with optical glasses or contact lenses in the initial stages. Conclusion: The knowledge regarding KCN was not satisfactory among our study population. There is a need to create an increased level of awareness for KCN. Health awareness programs and community campaigns should be organized to raise awareness regarding KCN and better eye health care utilization.

## **Keywords**

Ophthalmology, Inflammation, Keratoconus, Blindness

## 1. Introduction

Keratoconus (KCN) is a degenerative bilateral, progressive disorder characterized by ectasia, thinning, and increased curvature of the cornea and is associated with loss of visual acuity, particularly with high-order aberrations [1]. The exact etiology of KCN is still in doubt, and a genetic basis has been suspected due to the clustering of cases within families and in twins [2] [3].

Epidemiological data shows that the incidence of KCN ranges from 1.25 to 25 per million-population depending upon the geographic location. The onset is usually at puberty that advances until the 3rd to 4th decade if life generally shows no gender predominance [4] [5] [6]. A study done by Kennedy *et al.* in Minnesota, USA, reported a prevalence of 0.054% [5]. In the Kingdom of Saudi Arabia, an incidence of 20 cases per 100,000 has been reported in Asir province with more severe and rapidly progressive cases [7]. Another study done in KSA among children and adolescents reported a prevalence of 4.79% [8].

KCN is reported to be associated with down syndrome, connective tissue disorders, Leber congenital amaurosis, Gas-Permeable (GP) contact lens wear, and chronic eye rubbing [1] [9]. KCN is usually classified as a non-inflammatory corneal ectatic disease and may remain undetected (subclinical) as asymmetric oblique astigmatism till puberty. Thus early detection and timely diagnosis are very much crucial to prevent the late complication of KCN. Many sophisticated tools for mapping the cornea contours are utilized in the diagnosis of KCN, such as the Ocular Response Analyzer, spectral-domain optical coherence tomography (OCT), Confocal microscopy, Fourier Transform Infrared (FTIR), and Optical Quality Analysis System [10]. The screening programs for KCN could utilize simple, inexpensive imaging devices like Keratometry (manual keratometer) and Corneal Topography. Authors have utilized some indices like Keratoconus Prediction Index (KPI-Klyce-Maeda group) and Rabinowithz KISA % index to discriminate Keratoconus and subclinical Keratoconus [11] [12].

One of the challenges that ophthalmologists face is halting disease progression in asymptomatic subclinical stages. Even though patients with KCN show significant myopia, it is not a criterion for its diagnosis. Asymmetrical corneal astigmatism and focal stromal thinning are considered a significant clinical presentation in KCN. In the diagnosis of KCN, symmetric astigmatism is not a criterion. Thus, diagnostic tools like tomography, topography, and pachymetry help evaluate corneal thinning and asymmetric astigmatism in KCN [13] [14]. In mild cases of KCN, rigid contact lenses or spectacles are usually sufficient to reduced visual acuity [15]. People need to be informed about the potential risks and importance of early detection of KCN. There is limited information on awareness and knowledge regarding KCN in Saudi Arabia among the general population. Hence this study was aimed to assess the understanding and knowledge concerning KCN in Saudi citizens.

## 2. Materials and Method

A cross-sectional observational study was conducted using a pre-tested and validated questionnaire in the Arabic language. Permission to conduct study was obtained from the Research and Ethics Committee of the institution. The study included only adult Saudi citizens who are aged above 18 years and those gave consent to participate. The questionnaire was sent online to participants through social network applications. A minimum sample size of 628 was calculated based in a pilot study conducted on 30 participants using the formula,

$$n = \frac{Z_{1-\alpha/2}\sqrt{P_{0}(1-P_{0})} + Z_{1-\beta}\sqrt{P_{\alpha}(1-P_{\alpha})}}{(P_{\alpha}-P_{0})^{2}}$$

We used a combination of convenience and snowball sampling techniques to collect data from different provinces of Saudi Arabia.

The original version of questionnaire was developed in English and was then validated. Content validity, face validity, and construct validity of the developed questionnaire were examined. An expert committee evaluation and Focused Group Discussions (FGDs) were conducted to determine content validity and face validity. The questionnaire showed good Internal consistency reliability (Cronbach's alpha = 0.861). The English version was then translated into Arabic language by a bilingual translator who was proficient in both English and Arabic language. Another expert back translated the Arabic version into English, which showed excellent linguistic validity. The questionnaire consisted of two sections; Section A included statement of confidentiality and Anonymity, followed by sociodemographic details and Section B had closed ended-items that measured the knowledge and associated variables regarding KCN. The items that measured knowledge were used to calculate total knowledge according to the responses where each correct answer for each item was given a score "1" and wrong answer a score "0". For calculating knowledge, we converted the total knowledge scores into percentages, which was then categorized "Good" (scores  $\geq$  80%), "Fair" (scores 60% - 79%), and "Poor" (<60%).

# **3. Statistical Analysis**

The responses obtained were entered in Microsoft Excel and was subjected to data cleaning was done to make the analysis easy. The data was then subjected to statistical analysis by an independent biostatistician. We used SPSS version 23 (IBM Corp. USA) for carrying out the required statistical analysis. Continuous

variables were expressed as means with standard deviations and categorical variables were presented as frequencies and percentages. Students "t" tests and Analysis of Variance (ANOVA) were used to evaluate the differences in mean knowledge scores across various sociodemographic characteristics. Association between categorical variables was tested using Pearson's Chi-square test. A probability value (p-value) less than 0.05 was considered to be statistically significant.

## 4. Results

Our study assessed the awareness and knowledge related to Keratoconus (KCN) among Saudi citizens. We received 1032 responses, but the final analysis included only 837 participants who had agreed to participate and also answered all the items in the questionnaire. The sociodemographic characteristics showed that 74.8% were females, and 25.2% were males. The age-wise distribution showed that 43.9% belonged to  $\geq$ 36 years group, 20.9% from 26 - 35 years, 32% from 18 - 25 years, and only 3.2% from <18 years. The distribution of participants according to region, education, and income status are given in (**Table 1**).

Our analysis showed that the awareness regarding KCN in our study population was only 49.2% (n = 412). Therefore we assessed the knowledge related to KCN its risk factors, symptoms, and management among these 412 participants only. The questionnaire had ten items related to knowledge, and each correct response for these items was given a score of 1, whereas wrong, incorrect answer

#### **Table 1.** Socio-demographic characteristics (n = 837).

		N	%
Gender	Female	626	74.79
	Male	211	25.21
Age	Less than 18	27	3.23
	18 - 25	268	32.02
	26 - 35	175	20.91
	36 or more	367	43.85
	Central	213	25.45
	Eastern	47	5.62
Region	Northern	266	31.78
	Southern	28	3.35
	Western	282	33.69
Education	Less than High school	8	0.96
	High school	130	15.53
	Bachelors and diploma	573	68.46
	Masters and PhD	126	15.05
Income status	Below average	33	3.94
	Average	562	67.14
	Above average	242	28.91

was given no score. Thus the total maximum score one participant could get was 10. The mean total knowledge score in our study was found to be  $4.12 \pm 2.6$ . We categorized the total score based on the percentages into Good ( $\geq$ 80%), fair (60% - 79%), and Poor (<60%). The analysis showed that only 11.7% had good knowledge, and 67.5% showed poor knowledge related to KCN (**Figure 1**).

We compared the knowledge scores between different sociodemographic characters (Table 2). There were no statistically significant differences noted

Table 2. Knowledge related to	> KCN and its	s relationship	with socio-	demographic	factors
(n = 412).					

		Knowledge				
		Good	Fair	Poor	Total	p value*
Gender	Female	37 (12%)	64 (20.8%)	207 (67.2%)	308 (100.0%)	
	Male	11 (10.6%)	22 (21.2%)	71 (68.3%)	104 (100.0%)	0.925
Age (years)	<18	1 (7.7%)	3 (23.1%)	9 (69.2%)	13 (100.0%)	
	18 - 25	11 (8.3%)	26 (19.7%)	95 (72.0%)	132 (100.0%)	0.530
	26 - 35	15 17.4%	19 22.1%	52 60.5%	86 100.0%	
	≥36	21 11.6%	38 21.0%	122 67.4%	181 100.0%	
Region	Central	12 11.4%	20 19.0%	73 69.5%	105 100.0%	0.973
	Eastern Northern Southern	3 13.0%	6 26.1%	14 60.9%	23 100.0%	
		16 12.2%	30 22.9%	85 64.9%	131 100.0%	
		1 7.1%	4 28.6%	9 64.3%	14 100.0%	
	Western	16 11.5%	26 18.7%	97 69.8%	139 100.0%	
Education level	Less than high school	0 0.0%	0 0.0%	4 100.0%	4 100.0%	0.750
	Bachelors and diploma	30 10.6%	59 20.9%	193 68.4%	282 100.0%	
	High school	10 15.6%	13 20.3%	41 64.1%	64 100.0%	
	Masters and PhD	8 12.9%	14 22.6%	40 64.5%	62 100.0%	
Income status	Above average	13 10.9%	28 23.5%	78 65.5%	119 100.0%	0.139
	Average	30 10.8%	56 20.2%	191 69.0%	277 100.0%	
	Below average	5 31.3%	2 12.5%	9 56.3%	16 100.0%	

\* a p value < 0.05 is considered statistically significant.



Figure 1. Knowledge related to Keratoconus (n = 412).

between male and female participants (p = 0.925). It was found that participants in the 26 - 35 years age group (17.4%) showed comparatively better knowledge scored compared to other age groups but didn't find any statistically significant association (p = 0.530). There were also no significant differences observed in knowledge scores in participants based on region (p = 0.973), education level (p = 0.750), and income status (p = 0.139) (Table 2).

Only 27.2% (n = 113) gave the correct definition of the Keratoconus, and 76% (n = 313) believed that KCN doesn't have a genetic predisposition. About 47.1% (n = 194) of the participants agreed that KCN would lead to myopia if not appropriately managed, and 42.5% (n = 175) believed that chronic eye inflammation is a risk factor KCN. It was observed that only 25.7% (n = 106) agreed that constant itching or rubbing of eyes would lead to KCN, and 57% (n = 235) cause vision deterioration if not treated on time.

The assessment of knowledge related to treatment of KCN showed that 61.4% (n = 253) of participants agreed that Keratoconus patients need constant follow-up with an ophthalmologist. It was observed that 28.9% (n = 119) of participants believed that eye drops could be used in the first stage of KCN, whereas 12.1% thought that corneal transplantation and 4.9% believed installing a ring in the cornea could be the treatment. Only 38.1% (n = 157) agreed KCN could be treated with optical glasses or contact lenses. The questions for treatment for advanced-stage showed that 71.8% (n = 296) of participants had the opinion that surgery could be the choice, whereas 11.4% (n = 47) mentioned it as eye drops, 6.3% (n = 26) as eyeglasses, and 5.8% (n = 24) as contact lenses. When we assessed the source of information related to KCN knowledge, 14.8% (n = 61) mentioned it as doctors or health care workers, 22.8% (n = 94) as social networks, and 20.1% (n = 83) friends or relatives.

## **5. Discussion**

To our knowledge, this was the first study that assessed the knowledge and awareness regarding Keratoconus (KCN) among the general population in the Kingdom of Saudi Arabia. The findings showed that the understanding and knowledge regarding KCN was poor among our study population irrespective of the sociodemographic characteristics. Studies show that the prevalence of KCN in the Saudi population is much higher compared to other Middle East countries [7] [8] [16] [17]. Despite the higher prevalence, our study population demonstrated poor knowledge regarding KCN.

Evidence shows that KCN has a multifactorial etiology that offers a high genetic predisposition, and several genomic loci and genes have been identified in this regard [2] [18] [19]. In our study, only 24% of the participants believed that KCN has genetic susceptibility, which shows poor knowledge of this eye disorder. The ethnic variations in the prevalence of KCN also strongly support the genetic predisposition. The prevalence of KCN in Caucasian populations was 50 in 100,000, whereas this was approximately double in Negroids and Latinos [20] [21]. However, some environmental factors also pose a greater risk for the development of KCN, such as eye rubbing, atopy, and UV light exposure [22] [23] [24] [25]. Remarkably, only very few participants were aware of the risk factors of KCN, in which 25.7% believed that frequent eye rubbing or itching causes the disease. Knowledge related to risk factors is essential as this would motivate the people to attend the screening, which could diagnose the disease at its incipient stage. Even though KCN is a progressive disorder, several treatments can improve the vision and, at times, reverse the damage [26]. Besides, the economic burden of KCN treatment is high to the patients and their caretakers, and hence, it is imperative to recognize those with the diseases at an early stage.

Currently, several ocular screening techniques such as corneal topography (CT) and biomechanical evaluation have been used, of which CT is commonly used for primary detection of KCN [27]. The diagnosis of subclinical KCN is often challenging for ophthalmologists. In subclinical KCN, there would be mild topographic changes in the cornea with the normal-appearing cornea in keratometry, retinoscopy, or slit-lamp biomicroscopy [28] [29]. In clinical KCN, topography, tomography, and pachymetry are used as the primary diagnostics, which would reveal corneal thinning and asymmetric astigmatism arising in the location of corneal protrusion [13].

The management of KCN depends on the stage of diseases and their progression. In the non-progressive stage, the first priority should be given for correction of vision, and in case of progressing type, emphasis should be given to slow the progression [30]. In the early stages of KCN, vision correction could be done with spectacles and soft contact lenses [31]. In our study, only 38.1% agreed that optical glasses and contact lenses could be used for vision correction at the early stages of KCN. In case of moderate-to-advanced KCN cases, vision correction, could be done using Rigid Gas-Permeable (RGP) contact lenses or scleral lenses, as these lenses are superior to neutralize the ocular aberrations associated with the keratoconic ectasia by creating a tear pool between the lens and the cornea [32]. Scleral lenses are usually recommended as they provide excellent vision and improved comfort compared to RGP contact lenses that often show intolerance, allergic reactions, corneal abrasions, and neovascularization [20] [33]. Another

treatment that is done to limit the progression of KCN is Corneal collagen crosslinking (CXL), which increases stromal rigidity, thereby stabilizing keratectasia progression [34]. Surgical correction of KCN is considered the last resort in the advanced stages if the vision is severely compromised. The corneal transplant is the common procedure done where the cornea from a donor is replaced partially or totally to the recipient [35]. Collagen crosslinking is also a promising and effective treatment for halting keratectasia's progression in KCN patients [36].

The study findings demonstrate a lack of knowledge among the Saudi population related to KCN, its risk factors, and management. There is a need to increase the public awareness and knowledge of KCN for prevention, early treatment, and utilization of eye care services in the Kingdom. This could minimize the visual impairment and unwanted economic burden for eye surgeries. World Sight Day is celebrated globally on the second Thursday of October to increase global attention on blindness and vision impairment [37]. There is a drastic improvement in health awareness programs in Saudi Arabia in the past years, and public eye health awareness campaigns should focus on social media and the Internet to cover the younger population. Currently, there are no national screening programs for eye disorders in Saudi Arabia; hence the author of this research suggests and requests the ministry of health to incorporate such programs as this can improve the awareness and knowledge related to KCN and other eye disorders.

Some of the limitations of the study should be addressed before generalizing our findings. As this is a cross-sectional survey, a major limitation of the study is selection bias as we included only participants who were willing to participate. Secondly, our study may have encountered response bias as the participants were asked to self-report. We tried to reduce this bias by incorporating closed-ended knowledge items with a simple, exhaustive set of answer options.

## 6. Conclusion

The study's findings show that awareness and knowledge related to KCN are lacking among the study population. The data we provided may help policymakers identify the target populations for KCN prevention and health education. Public health awareness and screening programs are needed in Saudi Arabia to address the lack of knowledge about KCN, its preventive and curative measures. As KCN has high genetic susceptibility, topographic screening in elementary schools could be done in children for early detection and disease stabilization.

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# **Conflicts of Interest**

None of authors have any conflict of interest to declare regarding the publication of this manuscript.

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## **List of Abbreviations**

KCN-Keratoconus

SPSS-Statistical Package for the Social Sciences

CT-Corneal topography

RGP-Rigid gas permeable

CXL-Corneal collagen cross-linking