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Awareness of Keratoconus Among the Diagnosed Cases of Keratoconus in Patients Visiting Al Shifa Trust Eye Hospital

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ABSTRACT

Keratoconus is a chronic, progressive, non-inflammatory, usually bilateral corneal disorder that causes stromal thinning that leads to corneal apical protrusion, irregular astigmatism, and decreased vision. Its etiology is multifactorial, and it is important to determine its awareness and its association with non-genetic, environmental risk factors to prevent it. **Objectives:** To determine the level of awareness of keratoconus among the diagnosed cases of keratoconus. **Methods:** This descriptive cross-sectional study was conducted at Al Shifa Trust Eye Hospital in five months using a consecutive sampling technique. SPSS version 22.0 was used for Data Analysis. The Pearson's Chi-square test was utilized for cross-tabulation. **Results:** Out of 135 patients, it was seen that participants with a higher level of education (P value 0.0029) and those with positive family history had overall better knowledge about the disease and specific knowledge about eye rubbing as an aggravating factor of the disease (P value 0.00249). In conclusion, overall, 48.1% % had poor knowledge, 34.8% had fair, and only 17% had good knowledge regarding the disease. **Conclusions:** Despite keratoconus being more common in younger individuals who have internet access, patients still had poor knowledge of the disease. Different strategies can be devised to increase awareness and prevent its progression by eliminating the non-genetic, environmental risk factors, such as eye rubbing and discussing compliance regarding the use of topical anti-allergic medications and regular follow-up visits.

INTRODUCTION

Keratoconus is a chronic, progressive, non-inflammatory, usually bilateral corneal disorder that causes stromal thinning that leads to corneal apical protrusion, irregular astigmatism, and decreased vision [1]. Its onset is usually before puberty, and it stabilizes after the fourth decade of life [2]. There are multiple management options ranging from conservative management, e.g, use of spectacles and Rigid Gas permeable lenses, to Interventional, e.g, Corneal cross (CXL and penetrating keratoplasty (PKP) that cause visual rehabilitation. [3] Patients typically encounter blurred vision, distortion, and glare; as the majority are young, the disease significantly restricts daily activities and diminishes quality of life [4, 5]. Its etiology is multifactorial, having a genetic predisposition along with multiple risk factors such as atopy, persistent eye rubbing, and exposure to ultraviolet light [6, 7]. There are different levels of understanding among patients regarding disease pathogenesis, risk factors, progression, and treatment options [8, 9]. It is important to determine the awareness of the disease and its association with non-genetic, environmental risk factors so that an important cause of corneal blindness can be prevented [10]. A Study conducted in Jeddah, Kingdom of Saudi Arabia, in 2021, revealed that 63.3% of the participants had poor, 31.9% had

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fair, and 4.8% had good knowledge regarding the disease. Almost 75.8% of the study participants used to rub their eyes, and only one third knew the fact that eye rubbing may lead to keratoconus [11]. Another recent study conducted in Aseer Province, Saudi Arabia, in the year 2023 revealed that 85.74% of the participants had poor and 14.26 % had a good level of awareness [12]. Another study conducted in the year 2022, in Medina, revealed that almost 94.1% of the study participants had poor 5.9 % had good knowledge regarding the disease. 27.8% had known that keratoconus and a history of allergies might have a relationship, and most of them, i.e., 27.5% had relatives with KC as their primary source of information, hence highlighting the association of better knowledge with positive family history [10]. A Study conducted in China revealed that 71.9 % participants with advanced keratoconus gave a history of eye rubbing due to a lack of awareness [13]. A Study regarding the association of keratoconus with other ocular disorders was conducted in Layton Rehmat Ullah Benevolent Trust LRBT, and Sir Ganga Ram Hospital, Lahore, Pakistan, showing that 66 out of 110 patients gave a positive history of eye rubbing, although an association between this habit and disease progression has long been established [14, 15]. Keratoconus is a progressive disease that can be halted with early diagnosis and prompt management. Even after being clinically diagnosed, many patients have limited knowledge regarding their disease, its progression, exacerbating factors, treatment options, and preventive measures. This study hypothesizes that patients who have a family history and who have a higher education level have a better understanding of the disease. It is important to evaluate the patients' knowledge, to explore associations between their level of awareness and level of education, along with their family history, and to identify patient education gaps leading to regular follow-ups, improve compliance with the treatment, avoid harmful behaviors such as eye rubbing, and screen the family members with similar symptoms.

This study aims to determine the level of awareness of keratoconus among diagnosed cases of keratoconus.

METHODS

This descriptive cross-sectional study was conducted at Al-Shifa Trust Eye Hospital for a duration of about 5 months, starting from 1/10/2024 to 1/3/2025. Ethical approval was obtained from the Ethical Review Committee of Al-Shifa Trust Eye Hospital, Rawalpindi (Ref. No: ERC-29/AST-24). Patients visiting the Cornea Department of the hospital for their follow-up checkup, who met the inclusion criteria, were recruited for the study. Informed consent was taken from the participants, and their confidentiality was ensured before the interview. A predesigned, pre-validated questionnaire was used that was amended according to our own population needs [12]. It was translated into the native language, Urdu, and then translated back into English to check for its validity by two other researchers. A pilot study was conducted on 15 participants to check the reliability of the questionnaire. Cronbach's alpha was calculated, which turned out to be 0.83; hence, the questionnaire was reliable. It contained three sections. The first section comprised three questions about personal details, including age, gender, and level of education. The second section contained four questions regarding the history of any allergies, types of allergies, treatment history, and family history of KC. The third section included ten questions about awareness regarding KC and its relation with allergies, recognition of eye rubbing as a risk factor, its complications, genetic predisposition, treatment options, and expectations from the treatment options. The responses were marked on a 5-point Likert scale. A single interviewer marked the responses to minimize the interviewer's bias. A sample size of 135 was calculated using the WHO calculator, with a 95% confidence interval, population proportion 14.26%, and absolute precision 6% [12]. Disease prevalence was taken as 5%, which is comparable in South Asia as well as the Middle East [12, 14]. All patients who were diagnosed with keratoconus for more than 6 months, were aged between 18 and 65, and had a K Max value > 48D on Galilei Scan topography were enrolled in the study. Patients with mental or verbal disability, those who could not fully comprehend the questions, had a language barrier, had no or less than a primary level of education, or who were eye care professionals, including ophthalmologists, ophthalmic nurses, optometrists, and opticians, were excluded. The responses were recorded on a 5-point Likert scale, and a total score was calculated. Data were analyzed using IBM SPSS version 22.0. The total score of awareness was calculated by adding the scores from each item of Section Three. Responses ranged from 1 point (strongly disagree) to 5 points (strongly agree), with higher scores indicating better knowledge. Scores were converted into percentages: <50%=poor, up to 70%=fair, and >70%=good knowledge [16]. Statistical analyses were performed using the Pearson Chi-Square test, with statistical significance set at $p \leq 0.05$.

RESULTS

About 135 participants were interviewed, and about 65.2% (n=88) were male,71.9% (n=97) were aged from 18-30 years, 28.1 % had an education level below secondary level, and about 18.5 % had a higher level of education. About 56.3% had a history of allergies. Out of these, most of them had ocular allergy. 51.9 % had previously received any form of treatment (including CXL and keratoplasty), and 27.4 % had a positive family history of KC (Table 1).

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Table 1: Demographic and Clinical Characteristics of Participants (n=135)

Variables	n (%)
Gender	
Male	88 (65.2)
Female	47 (34.8)
Age group (years)	
18-30	97 (71.9)
>30	38 (28.1)
Education level	
Below secondary	38 (28.1)
Intermediate	72 (53.3)
Higher	25 (18.5)
History of allergies	76 (56.3)
Ocular allergy (most common)	–
Previous treatment (CXL/keratoplasty)	70 (51.9)
Positive family history	37 (27.4)

Of 135 participants, only 10.4% had heard its name before their own diagnosis, while 89.6% did not. Approximately 41.5% recognized that keratoconus is actually corneal thinning. Specific knowledge about its association with allergy was noted by 40%. 41.5% claimed to know that it causes a permanent decrease in vision. Approximately 59.3% knew that eye rubbing worsens it and increases the complications, while 40.7% expressed uncertainty. Only 28.9% knew that it stabilizes with age. 18.5 %of the participants knew that it has a genetic predisposition (Table 2).

Table 2: Knowledge and awareness about keratoconus (n=135)

Q#	Questions	Response	Frequency (%)
Q1	Have you heard about KC before?	No	121 (89.6)
		Yes	14 (10.4)
Q2	Does KC mean corneal thinning?	Poor knowledge	79 (58.5)
		Good knowledge	56 (41.5)
Q3	Does KC have a relation with allergies?	No	81 (60.0)
		Yes	54 (40.0)
Q4	Does KC cause a permanent decrease in vision?	No	79 (58.5)
		Yes	56 (41.5)
Q5	Does eye rubbing worsen KC?	Poor knowledge	55 (40.7)
		Good knowledge	80 (59.3)
Q6	Does eye rubbing worsen complications of KC?	Poor knowledge	55 (40.7)
		Good knowledge	80 (59.3)
Q7	Does KC stabilize with age?	No	96 (71.1)
		Yes	39 (28.9)
Q8	Does KC have a genetic predisposition?	No	110 (81.5)
		Yes	25 (18.5)
Q9	CXL only stops the progression of KC and does not cure it?	No	51 (37.8)
		Yes	84 (62.2)
Q10	Knowledge regarding treatment options	Poor knowledge	82 (60.7)
		Good knowledge	53 (39.3)

Overall, 48.1% % had poor knowledge, 34.8% had fair, and only 17% had good knowledge regarding the disease (Figure 1).

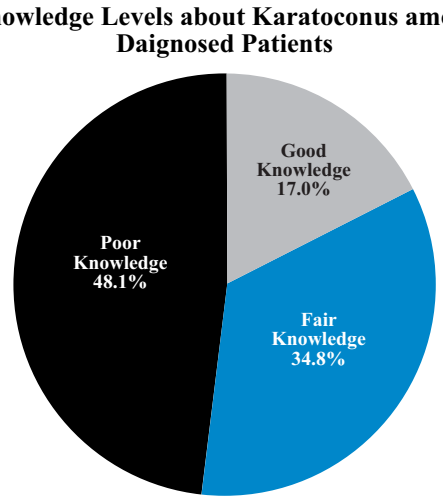

Figure 1: Knowledge Levels about Keratoconus among Diagnosed Patients

With dichotomization to Agree versus Disagree/Uncertain, education had a significant association with eye rubbing. The proportion of the participants who reported frequent eye rubbing as a preventable cause of keratoconus was 64.9% among those with secondary or higher education and 44.7% among those with below secondary education. This dissimilarity was statistically significant (χ^2 (1) =9.74, p=0.002)(Table 3).

Table 3: Association between Education Level and Knowledge Regarding Keratoconus (n=135)

Education level	Agree n (%)	Disagree/ Uncertain n (%)	Total n (%)
Below secondary	17 (44.7)	21 (55.3)	38 (28.1)
Secondary & above	63 (64.9)	34 (35.1)	97 (71.9)
Total	80 (59.3)	55 (40.7)	135 (100.0)

Chi-square test: $\chi^2(1) = 9.74$, $p = 0.002$.

Participants with a positive family history of keratoconus tend to know about its exacerbating effect with eye rubbing. The association was significant when analyzed across the full five categories (χ^2 (4)=11.97, p=0.018). This was lost when responses were collapsed in a 2×2 configuration and suggests that it is essential to maintain the original response distribution to capture subtle yet meaningful effects (Table 4).

Table 4: Association between Family History of Keratoconus and Knowledge about Eye Rubbing (n=135)

Family History	Strongly Disagree n (%)	Disagree n (%)	Don't Know n (%)	Agree n (%)	Strongly Agree n (%)	Total n (%)
Yes	13 (37.1)	0 (0.0)	0 (0.0)	8 (22.9)	14 (40.0)	35 (25.9)
No	19 (19.0)	17 (17.0)	6 (6.0)	18 (18.0)	40 (40.0)	100 (74.1)
Total	32 (23.7)	17 (12.6)	6 (4.4)	26 (19.3)	54 (40.0)	135 (100.0)

*Chi-square test: $\chi^2(4) = 11.97$, p=0.018

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DISCUSSIONS

The purpose of this study was to determine the awareness level of keratoconus among diagnosed patients who were coming to the outpatient department of Al Shifa Trust Eye Hospital on their follow-up visits. Regarding knowledge of their disease, overall, 51.8% had a satisfactory level of understanding, which included the participants who had fair (34.8%) and good knowledge (17%) of the disease. Only 40% knew the disease causes corneal thinning and weakness, leaving most unaware of its impact on their eyes. Only 40% linked it to allergies, and few knew its progressive, permanently blinding nature, which is an alarming gap. About 81.5% were aware that there is some association with family history. Specific knowledge regarding stabilization of the disease with progressing age was noted by only 28.9%, pointing to the cause of demanding CXL despite the stabilization of their disease due to age. Most of them acknowledged CXL as the treatment option, followed by spectacles, contact lenses, and surgery. Many participants (62.2%) knew that CXL halts disease progression rather than curing it permanently, but few believed otherwise. The study revealed that participants who had good knowledge were mostly younger patients, aged 18–30 years, who had a higher level of education and positive family history. A similar level of awareness was observed in a study conducted at Aseer province, showing 14.26% of participants having good knowledge of their disease [12]. Whereas a study conducted by Alamri *et al.* at Abha reported only 8.1% participants having satisfactory awareness, and more than 90% had poor awareness [17]. While Al Rashed et al. reported a good level of understanding (85.5%) regarding keratoconus among the Saudi population [18]. About 59.3% recognized eye rubbing as harmful, with educated participants and those with a family history showing better awareness of its sight-threatening impact. Alamri *et al.* reported that 57% of participants in Aseer province being aware of this preventable aggravating factor, which is comparable to our study [12, 19]. While Kordi *et al.* reported much lower numbers of aware participants (28.9%) in Medina [10]. Very few, only about 10% of the patients, had heard the name of the disease before their own diagnosis even those who had a positive family history which clearly exhibits that there is lack of overall awareness of keratoconus, and patients often assume it to be a usual refractive error [20]. This is the first study in Rawalpindi to assess keratoconus awareness through interviews, ensuring inclusion of those unable to complete questionnaires or lacking internet access. However, some limitations remain. Firstly, the questionnaire was administered only to participants who actually came for follow-up visits, so it can be assumed that those who knew the devastating nature of the disease were enrolled in the survey. Secondly, the questionnaire was undertaken from a single center hospital, which might lead to unequal distribution of participants; hence, the results cannot be generalized to the whole population of Pakistan. The study can be improved further by increasing the sample size and making it a multicenter study involving multiple centers across Pakistan.

CONCLUSIONS

Keratoconus is a chronic progressive disease and many patients, even after being clinically diagnosed, have limited knowledge regarding its progression, risk factors, treatment options and preventive measures. This study highlights the gaps between patient and health care providers so different strategies can be devised to increase regular follow ups, improve compliance to the treatment, avoid harmful behaviors such as eye rubbing and screen the family members with similar symptoms.

Authors Contribution

Conceptualization: TA
Methodology: HGS, SFB, NY
Formal analysis: TA, FA, MAM
Writing review and editing: TA

All authors have read and agreed to the published version of the manuscript

Conflicts of Interest

All the authors declare no conflict of interest.

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