






Public knowledge about keratoconus: a cross-sectional online survey in Brazil

Conhecimento público sobre o ceratocone: um questionário online transversal no Brasil

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ABSTRACT

Objective: To evaluate public knowledge of keratoconus in Brazil and identify gaps to guide future educational strategies.

Methods: A cross-sectional online survey, based on the 2015 Global Consensus on Keratoconus, was distributed via social media and an ophthalmology bulletin. Adults (≥ 18 years) participated anonymously after providing informed consent. The questionnaire assessed demographics, ocular history, and keratoconus-related knowledge. Descriptive statistics summarized the data, and associations were analyzed using chi-square and nonparametric tests (5% significance level).

Results: A total of 879 individuals (mean age: 45.9 ± 15.2 years; 72.0% female) participated. Self-reported keratoconus was present in 22.6%, while 31.5% had heard of the disease and 45.8% were unfamiliar with it. Ocular allergy affected 42.1%, and 31.3% reported frequent eye rubbing. Although 83.1% recognized vision-related symptoms, only 52% identified keratoconus as a multifactorial condition. Misconceptions were common: 55.0% believed it causes blindness, 41.8% thought contact lenses prevent progression, and 20.6% considered surgery the only treatment. Awareness of corneal cross-linking (31.5%) and intracorneal rings (22.1%) was limited. Higher education and previous awareness were associated with better knowledge ($p < 0.01$), while older age correlated with lower awareness.

Conclusion: Significant knowledge gaps and misconceptions about keratoconus remain in Brazil. Targeted educational campaigns are needed to promote early diagnosis and correct misinformation.

RESUMO

Objetivo: Avaliar o conhecimento do público sobre o ceratocone no Brasil e identificar lacunas para orientar futuras estratégias educacionais.

Métodos: Uma pesquisa transversal on-line, baseada no Consenso Global sobre Ceratocone de 2015, foi distribuída por meio das redes sociais e de um boletim de oftalmologia. Adultos (≥ 18 anos) participaram anonimamente após fornecerem consentimento informado. O questionário avaliou dados demográficos, histórico ocular e conhecimento relacionado ao ceratocone. Estatísticas descritivas resumiram os dados, e as associações foram analisadas utilizando testes qui-quadrado e não paramétricos (nível de significância de 5%).

Resultados: Participaram 879 indivíduos (idade média: $45,9 \pm 15,2$ anos; 72,0% mulheres). O ceratocone autodeclarado estava presente em 22,6%, enquanto 31,5% já tinham ouvido falar da doença e 45,8% não estavam familiarizados com ela. A alergia ocular afetava 42,1%, e 31,3% relataram esfregar os olhos com frequência. Embora 83,1% reconhecessem sintomas relacionados à visão, apenas 52% identificaram o ceratocone como uma condição multifatorial. Equívocos eram comuns: 55,0% acreditavam que a doença causa cegueira, 41,8% pensavam que as lentes de contato previnem a progressão e 20,6% consideravam a cirurgia o único tratamento. O conhecimento sobre o cross-linking da córnea (31,5%) e os anéis intracorneais (22,1%) era limitado. O nível de escolaridade mais elevado e o conhecimento prévio estavam associados a um melhor conhecimento ($p < 0,01$), enquanto a idade mais avançada se correlacionava com menor conhecimento.

Conclusão: Persistem lacunas significativas de conhecimento e equívocos sobre o ceratocone no Brasil. São necessárias campanhas educacionais direcionadas para promover o diagnóstico precoce e corrigir a desinformação.

INTRODUCTION

Keratoconus (KC) is a progressive corneal ectatic disorder characterized by thinning and conical protrusion of the cornea, resulting in irregular astigmatism and visual distortion.^(1,2) Onset typically occurs during adolescence or early adulthood and may significantly impair quality of life, academic performance, and professional functioning. In advanced cases, untreated KC may lead to severe visual loss or legal blindness.⁽³⁾ Early diagnosis is critical, as timely interventions, particularly corneal collagen cross-linking (CXL), can halt progression and preserve vision, potentially avoiding the need for corneal transplantation.^(4,5)

Despite diagnostic and therapeutic advances, KC remains poorly understood by the general public. Its relatively lower recognition contributes to low awareness. Global prevalence estimates range from 0.2 to 4,790 per 100,000 persons to as high as 5% in some populations.⁽⁶⁾ In Brazil, although epidemiological data are limited, KC is recognized as a significant cause of visual impairment among young adults.⁽⁷⁾

Lack of public knowledge may delay care and worsen outcomes.⁽⁸⁾ Risk factors such as frequent eye rubbing are often underestimated, while disease severity may be exaggerated, causing unnecessary fear or stigma.^(9,10) Understanding public perceptions and correcting misconceptions are essential for effective health education.⁽⁸⁾ Initiatives like the global Violet June campaign promote early diagnosis and discourage harmful behaviors.⁽¹¹⁾ However, their success depends on baseline knowledge, which remains poorly documented in Brazil.^(12,13)

Similar international surveys have also revealed limited public understanding of KC, with studies in Europe and the Middle East reporting low knowledge levels and frequent engagement in risk behaviors such as eye rubbing.^(9,14,15)

This study aimed to evaluate public knowledge of KC in Brazil and identify gaps to guide future educational strategies.

METHODS

A descriptive cross-sectional survey was conducted between June and August 2024 to assess KC knowledge in the general Brazilian population. The study followed the Declaration of Helsinki and received approval from the Institutional Research Ethics Committee (protocol no. 6.584.843/2023; CAAE: 76077522.7.0000.5258). Participation was anonymous and voluntary, with electronic informed consent obtained at the start of the

questionnaire. A structured questionnaire was developed specifically for this study, based on key topics from the 2015 Global Consensus on Keratoconus and Ectatic Diseases (Supplementary Material - Chart 1S). It was written in Portuguese, reviewed by two ophthalmologists, and pilot-tested on laypersons for clarity. The final instrument included 25 main questions across three domains: participant demographics (age, sex, education, and region); ocular history (presence or knowledge of KC, allergy history, eye rubbing frequency, and refractive correction); and KC knowledge (etiology, symptoms, treatments, and common misconceptions). Knowledge questions were presented as multiple-choice or true/false items. All participants, regardless of prior awareness, were required to respond to knowledge questions, even if by guessing.

The survey was hosted on Google Forms and distributed through social media platforms (Facebook, WhatsApp, Twitter) and via an ophthalmology newsletter (*Oftalmologia em Foco*). A convenience sampling strategy aimed to reach both individuals with KC and members of the general public. Inclusion criteria included age ≥ 18 years, Brazilian residency, and Portuguese comprehension. A total of 912 responses were received; after excluding incomplete responses and ineligible participants, 879 were included in the final analysis (3.38% margin of error and 95% confidence level).

The primary outcomes were the proportion of correct and incorrect answers to each knowledge question and their association with demographic or clinical variables. Misconceptions were defined as incorrect beliefs that contradicted scientific consensus.

Data were analyzed using Statistical Package for the Social Sciences (SPSS) version 20.0. Categorical variables were presented as frequencies and percentages, while age was summarized as mean \pm standard deviation. Associations between knowledge and participant characteristics were assessed using chi-square or Fisher's exact tests. Nonparametric tests (Kruskal-Wallis with Dunn-Bonferroni post-hoc corrections) were used for continuous or ordinal comparisons when appropriate. Spearman's correlation was used to evaluate associations between numerical variables. All tests adopted a 5% significance level.

RESULTS

Demographics and ocular history

A total of 879 participants completed the survey (Table 1). The mean age was 45.9 years (± 15.2), ranging from 18 to 93 years. Most respondents were female (72.0%). Regarding

education level, 28.9% had completed secondary education, while 23.1% had postgraduate degrees. A history of ocular allergy was reported by 42.1%, and 31.3% reported rubbing their eyes frequently (≥ 3 times/day). Concerning refractive correction, 62.1% used glasses and only 5.2% wore contact lenses.

Table 1. Demographic, clinical, and keratoconus knowledge characteristics

Variable	
Sex, n (%)	
Female	632/878 (72.0)
Male	245/878 (27.9)
Other	1/878 (0.1)
No information	1
Age, years	
Mean \pm SD	45.9 \pm 15.2
Median (IQR)	45.0 (33.0-58.0)
n	879
Education level, n (%)	
Primary school	60/879 (6.8)
Some secondary school	73/879 (8.3)
Completed secondary school	254/879 (28.9)
Some college/university	103/879 (11.7)
Completed college/university	186/879 (21.2)
Postgraduate	203/879 (23.1)
History of allergy, n (%)	
No	509/879 (57.9)
Yes	370/879 (42.1)
Eye rubbing, n (%)	
Never	136/879 (15.5)
Rarely (1-2 times/day)	468/879 (53.2)
Frequently (3-6 times/day)	180/879 (20.5)
Always	95/879 (10.8)
Use of glasses or contact lenses, n (%)	
Yes, glasses	546/879 (62.1)
Yes, contact lenses	46/879 (5.2)
Yes, both	70/879 (8.0)
No	217/879 (24.7)
Keratoconus awareness/diagnosis, n (%)	
Yes, I have keratoconus	199/879 (22.6)
I know what keratoconus is, but I don't have it	277/879 (31.5)
No	403/879 (45.8)
Knows someone with keratoconus, n (%)	
No	515/879 (58.6)
Yes	364/879 (41.4)

SD: standard deviation; IQR: interquartile range.

Awareness and personal experience

Approximately 22.6% (199/879) of respondents had been self-reported diagnosed with KC, 31.5% (277/879) were familiar with the disease but had not been diagnosed, and 45.8% (403/879) had never heard of it. Additionally, 41.4% reported knowing someone with KC.

Knowledge and misconceptions

When asked about the cause of KC, 51.7% correctly identified both genetic predisposition and environmental factors (e.g., eye rubbing) as contributors, while 32% selected

environmental causes only. Notably, older respondents and those with lower educational levels were more likely to misunderstand the multifactorial etiology ($p < 0.001$).

Knowledge of symptoms was relatively high, with 83.1% recognizing blurred vision and image distortion as characteristic signs. However, 41.8% mistakenly believed that eye pain and inflammation are typical features. This misconception was more common among those who did not have KC and those with lower levels of education ($p < 0.001$).

In terms of laterality, 63.9% correctly noted that KC affects both eyes asymmetrically. Regarding disease progression, 55.0% believed that KC generally causes blindness, an overestimation that reflects significant public misunderstanding of disease prognosis.

Risk behaviors and treatment awareness

Eye rubbing was recognized by 88.7% of participants as a potential cause or aggravating factor. Nonetheless, this behavior remained prevalent, with 31.3% of individuals rubbing their eyes frequently. Among frequent eye rubbers, awareness of the risks was paradoxically lower ($p < 0.05$).

Participants showed limited familiarity with modern treatment options. Only 31.5% had heard of corneal collagen CXL, and just 22.1% were aware of intracorneal ring segments. Among KC patients, 40.7% had never heard of CXL, and 20.7% were unaware of intracorneal ring implantation.

Additionally, 41.8% believed that wearing contact lenses could slow or stop the progression of KC, another common misconception. Furthermore, 20.6% of KC patients believed that the condition is only treatable through surgery, and 13.1% thought that corneal transplantation was the only surgical option.

A subgroup analysis demonstrated that higher educational attainment and previous knowledge of KC were significantly associated with more accurate responses across most knowledge items ($p < 0.01$). Conversely, older age was associated with lower awareness of both symptoms and therapeutic options.

Multidisciplinary care and psychological support

The importance of adjunctive therapy was better understood. 85.0% of respondents believed that treating ocular allergy with lubricants and antihistamines is essential for KC care. In addition, 90% believed that psychological or psychiatric support could help patients cope with the emotional burden of the disease.

Overall knowledge

The mean overall knowledge score (calculated based on the number of accurate answers across 14 core items) showed a statistically significant correlation with younger age, higher education, and personal experience with the disease ($p < 0.05$), as shown in table 2.

Table 2. Summary of keratoconus knowledge score by participant characteristics

Characteristic	Mean \pm SD	Median (IQR)	n	p-value
Total	9.6 \pm 2.3	10.0 (8.0-11.0)	878	
Sex				0.048*
Female [¶]	9.5 \pm 2.2	10.0 (8.0-11.0)	631	
Male [‡]	9.9 \pm 2.4	10.0 (8.0-12.0)	245	
Other	12.0 \pm 0.0	-	1	
Education level				<0.001*
Primary school [¶]	8.1 \pm 1.8	8.0 (7.0-9.0)	60	
Incomplete secondary school [¶]	8.2 \pm 2.1	9.0 (7.0-10.0)	73	
Complete secondary school [§]	8.9 \pm 2.0	9.0 (7.0-10.0)	253	
Incomplete college/university [§]	9.5 \pm 2.2	10.0 (8.0-11.0)	103	
Complete college/university [‡]	10.2 \pm 2.1	10.0 (9.0-12.0)	186	
Postgraduate [‡]	10.9 \pm 2.1	11.0 (10.0-13.0)	203	
History of allergy				<0.001†
No	9.3 \pm 2.2	9.0 (8.0-11.0)	508	
Yes	10.0 \pm 2.3	10.0 (8.0-12.0)	370	
Eye rubbing				<0.001*
Never [‡]	10.4 \pm 2.7	11.0 (8.0-13.0)	136	
Rarely (1-2 times/day) [§]	9.6 \pm 2.2	10.0 (8.0-11.0)	468	
Frequently (3-6 times/day)	9.4 \pm 2.2	9.0 (8.0-11.0)	179	
Always [¶]	8.7 \pm 2.0	9.0 (7.0-10.0)	95	
Use of glasses or contact lenses				<0.001*
Yes, glasses [¶]	9.3 \pm 2.2	9.0 (8.0-11.0)	546	
Yes, contact lenses [‡]	10.5 \pm 2.2	11.0 (9.0-12.0)	46	
Yes, both [‡]	10.7 \pm 2.0	11.0 (9.0-12.0)	70	
No [¶]	9.9 \pm 2.3	10.0 (8.0-12.0)	216	
Knows or has keratoconus				<0.001*
Yes, I have keratoconus [‡]	10.4 \pm 2.0	11.0 (9.0-12.0)	199	
I know what it is, but don't have it [‡]	10.3 \pm 2.3	10.0 (9.0-12.0)	277	
No [¶]	8.7 \pm 2.0	9.0 (7.0-10.0)	402	
Knows someone with keratoconus				<0.001†
No	8.9 \pm 2.1	9.0 (7.0-10.0)	514	
Yes	10.6 \pm 2.2	11.0 (9.0-12.0)	364	

p-value from *Kruskal-Wallis or †test Mann-Whitney; ‡, § and ¶ indicate groups with significantly different means (Dunn-Bonferroni post-hoc).

DISCUSSION

This study presents a comprehensive overview of the knowledge of Brazilian population on KC, a relatively under-recognized condition despite its clinical significance. The results reveal substantial gaps and misconceptions among both individuals diagnosed with KC and the general public. To our knowledge, this is the first large-scale cross-sectional survey in Brazil to quantitatively assess awareness and understanding of KC in a diverse sample, including both patients and non-patients.

The finding that 45.8% of respondents had never heard of KC underscores a critical need for public health education. Although the disease is less prevalent than

refractive errors or cataract, its progressive and potentially sight-threatening nature, particularly if not diagnosed early, makes timely recognition essential.⁽¹⁶⁾ The lack of awareness may delay diagnosis and treatment, increasing the risk of vision loss and reducing quality of life.⁽¹⁷⁾

Among those who had heard of the disease, many held misconceptions about its causes and treatment. Although the majority recognized blurred vision and visual distortion as symptoms, only 52% correctly identified the multifactorial etiology of KC, and 55% incorrectly believed it inevitably leads to blindness. These findings highlight the need to clarify not only the nature of the disease but also its prognosis, particularly emphasizing that KC is not a blinding disease when properly managed.⁽¹⁸⁾

There are several refractive surgical approaches available for the treatment of KC, including surface ablation, intracorneal ring segments, phakic intraocular lenses, and corneal CXL, which can be used alone or in various combinations depending on the patient's corneal regularity and disease stage.⁽¹⁹⁾ An important observation is the low awareness of modern therapeutic options, even among those diagnosed with the disease. Corneal collagen CXL, currently the gold standard for halting KC progression, was unknown to 40.7% of patients with the condition.⁽²⁰⁾ Similarly, 20.7% were unaware of intracorneal ring implants, and 13.1% believed that corneal transplantation is the only surgical option. These data suggest that information is either not reaching patients adequately or is not being retained, raising concerns about communication strategies during consultations.⁽²¹⁾

The study also sheds light on the persistence of harmful behaviors, such as frequent eye rubbing. While 88.7% of respondents acknowledged that eye rubbing can cause or worsen KC, nearly a third still reported engaging in this behavior daily. This gap between knowledge and behavior emphasizes the need for practical guidance on how to change habits, especially in patients with allergic conjunctivitis.⁽²²⁾ It also suggests that risk communication alone may be insufficient without personalized behavioral interventions. This behavioral contradiction, wherein patients acknowledge harmful habits yet persist in them, finds further context in the international study by Baenninger et al., which revealed that none of the KC patients surveyed met the minimum disease knowledge standard expected by specialists.⁽¹⁴⁾

Another noteworthy point is the role of education and exposure in shaping disease understanding. Participants with higher educational attainment and personal experience with KC (either self or via acquaintance) consistently

performed better across knowledge domains. In contrast, older adults and individuals with lower education levels were more prone to misconceptions. These findings are consistent with the broader literature on health literacy and reinforce the need for tailored educational materials that address different audiences, including simplified language and visual aids for those with limited health literacy.^(8,23)

Encouragingly, most respondents acknowledged the importance of psychological and multidisciplinary support, with 92% agreeing that mental health support can aid patients in coping with KC. This aligns with previous qualitative studies suggesting that KC, particularly in younger individuals, can lead to emotional distress, reduced self-esteem, and anxiety about vision loss.⁽²⁴⁾ The recognition of this need by both patients and non-patients supports integrating psychosocial care into KC management protocols.⁽²⁵⁾

Even among individuals diagnosed with KC, key misconceptions, such as believing it inevitably leads to blindness or is only treatable by surgery, remained common, highlighting serious gaps in patient education. These findings suggest that clinical consultations may not be effectively conveying essential information. Given that KC often begins in adolescence, these results also support the implementation of school-based education and screening programs. Targeted public health policies in educational settings could promote early detection, discourage harmful behaviors like eye rubbing, and improve long-term visual outcomes.

From a public health standpoint, the findings provide strong support for awareness campaigns such as the international initiative Violet June, which promotes early diagnosis and highlights modifiable risk factors.⁽¹¹⁾ However, the effectiveness of such campaigns depends on reaching populations with little or no prior awareness, precisely the group most at risk of being overlooked. This study provides evidence-based direction for campaign design, particularly suggesting emphasis on debunking myths (e.g., blindness inevitability), reinforcing modern treatments, and highlighting the role of prevention (e.g., managing allergies, avoiding eye rubbing).

The results also have implications for clinical practice. Ophthalmologists and optometrists should ensure that all patients receive complete, understandable information about their diagnosis and treatment options. Tools such as printed educational materials, brief videos, or patient support groups may help reinforce messages conveyed during consultations. Clinicians should also actively correct misconceptions and check patient understanding during follow-up visits.⁽⁸⁾

Limitations

This study has limitations. The convenience sampling strategy and online survey format may have introduced selection bias, favoring individuals with higher education or digital access. The sample also included a larger proportion of KC patients than in the general population, which may have inflated the overall knowledge level. Furthermore, the self-reported nature of responses may have introduced social desirability bias or inaccuracies in diagnosis status. Nonetheless, the inclusion of both patients and laypersons allowed meaningful comparisons and the identification of knowledge gaps across subgroups.

CONCLUSION

This study reveals significant gaps in the Brazilian population's knowledge about keratoconus, particularly regarding its etiology, prognosis, and available treatments. While some understanding exists, misconceptions remain prevalent, even among patients. These include the belief that keratoconus inevitably leads to blindness or that it is only treatable with surgery. Low awareness of effective treatments such as corneal cross-linking and intracorneal rings highlights the need for improved communication between healthcare providers and patients. Additionally, the strong association between knowledge and factors such as educational level, age, and prior exposure to keratoconus emphasizes the importance of targeted public health strategies. Ultimately, improving knowledge about keratoconus has the potential to enhance clinical outcomes, reduce psychological burden, and support long-term visual health.

AUTHORS'S CONTRIBUTION

All authors contributed to the development of this study, including data collection, analysis, and manuscript preparation. Each author provided important intellectual input and approved the final version of the manuscript. João Batista Ramos da Fonseca Filho played a central role in all stages of the work, including study conception, design, data analysis, and writing of the manuscript.

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