

# Preliminary demographics for patients with keratoconus attending a university-based clinic in Johannesburg, South Africa



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**Background:** Keratoconus (KC) is a visually debilitating disease if left undiagnosed and untreated. Early intervention is necessary to ensure a good quality of life for those afflicted by the disease. Although much research has been done in other parts of the world, there is a paucity in the literature that describes the disease from a South African perspective.

**Aim:** The aim of this study was to provide the demographics of KC patients attending a university-based contact lens clinic between January 2007 and December 2017.

**Setting:** Patients diagnosed with KC ( $N = 206$ ) at a university-based contact lens clinic in Johannesburg, South Africa, were included in this analysis.

**Methods:** A retrospective analysis of clinical records of 206 KC patients was conducted. Demographic data on race, gender, age and severity of disease were analysed and presented.

**Results:** The majority of patients with KC that attended the clinic were female (53%), of mainly African (74%) descent and in their second decade of life. The average age at first visit was  $24.0 \pm 8.53$  and  $22.9 \pm 7.46$  years for males and females, respectively. There was no significant difference in average age between male and female patients ( $p > 0.05$ ). Patients in the first and second decade of life presented at first visit with a greater severity of disease when compared with those in the third decade or older.

**Conclusion:** There is a dire need for larger epidemiological studies to be conducted on South African patients with KC so that early intervention becomes possible. This would greatly influence the quality of life for these patients and positively impact the socio-economic status of the country.

**Keywords:** South Africa; Keratoconus; demographics; Johannesburg; Oculus Pentacam; university-based clinic.

## Introduction

*Kerato* (cornea) and *Konos* (cone) are Greek words from which the term keratoconus (KC) is derived. The literal translation, that is, cone-shaped cornea, is the fundamental characteristic that defines the disease. It is well established that KC is a bilateral, asymmetrical, non-inflammatory thinning of the cornea, which leads to high amounts of irregular corneal astigmatism, corneal bulging and sometimes distortion or scarring in various parts of the cornea.<sup>1</sup>

Keratoconus remains poorly defined in several aspects. As presented in many reviews of KC,<sup>1,2,3</sup> gender predominance remains uncertain. While some studies show no difference in sex,<sup>4</sup> others show a preponderance for males.<sup>5,6</sup> The prevalence of KC varies from 0.3 per 100 000 in colder climates such as Russia<sup>7</sup> to 2300 per 100 000 (2.3%) in warmer climates such as India.<sup>8</sup> However, generally KC is reported to have a prevalence of 54 per 100 000 people.<sup>2,9</sup> The prevalence numbers vary greatly depending on the population studied and the methods used to diagnose the condition.<sup>2</sup>

Keratoconus is a multifactorial disease, and much research has been done on many different aspects in an effort to better understand its complexities; however, there is little in the literature that represents the South African keratoconic population. It is therefore necessary for research to be done on South Africans so that eventually we can have a much better understanding of how the disease affects the South African population specifically. As far as we are aware, there have not been any studies conducted on the demographics of South African keratoconics. The aim of this

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study was to provide the demographics of KC patients who attended a university-based contact lens clinic in Johannesburg, South Africa.

## Methods

This study, as part of a broader investigation of KC, received ethical clearance from the Ethics Committee of the university. Patients also routinely provide informed consent to use their clinical data when attending the clinic as it is a university clinic. Clinical records from the contact lens clinic at the University of Johannesburg (UJ) (from January 2007 to December 2017) were analysed retrospectively. Every patient that attended the contact lens clinic underwent a thorough eye examination, which included a tomography evaluation with the Pentacam 70700 (Oculus, Wetzlar, Germany). Those patients who were diagnosed as having KC and had at least one good quality Pentacam scan were included in the analysis. The Pentacam scan was deemed viable if the quality specification (QS) was 'OK'. Patients were excluded if they had a differential diagnosis of pellucid marginal degeneration, corneal surgery or poor quality Pentacam scans. It was necessary to include only those patients with good quality scans to enable the grading of KC. The Pentacam did not trigger automatically if the cornea was already in the advanced stages of the disease and the cornea was severely distorted and/or scarred. There are many methods to grade KC<sup>10,11,12,13</sup> and there is currently no consensus on which method is best to use.<sup>14</sup> For the purposes of this study, the methodology of the Collaborative Longitudinal Evaluation of Keratoconus (CLEK)<sup>13</sup> study was used as it is a popular method of choice for grading the severity of KC.<sup>15,16,17</sup> This method is based on the keratometry measurement of the steepest meridian. Table 1 summarises how the CLEK method is used to grade KC. Severity of disease and demographic data (gender, race and age) were analysed for 206 patients diagnosed with KC. All statistical analysis was conducted using Statistica 13.3 (TIBCO). Normality of data (for patient age) was determined with the Shapiro–Wilks test.

## Ethical considerations

This study, as part of a broader investigation of keratoconus, received ethical clearance from the Ethics Committee of the Faculty of Health Sciences of the University of Johannesburg. Patients also routinely provide informed consent to use their clinical data when attending the clinic as it is a university clinic. Ethical Clearance number: REC-241112-035.

## Results

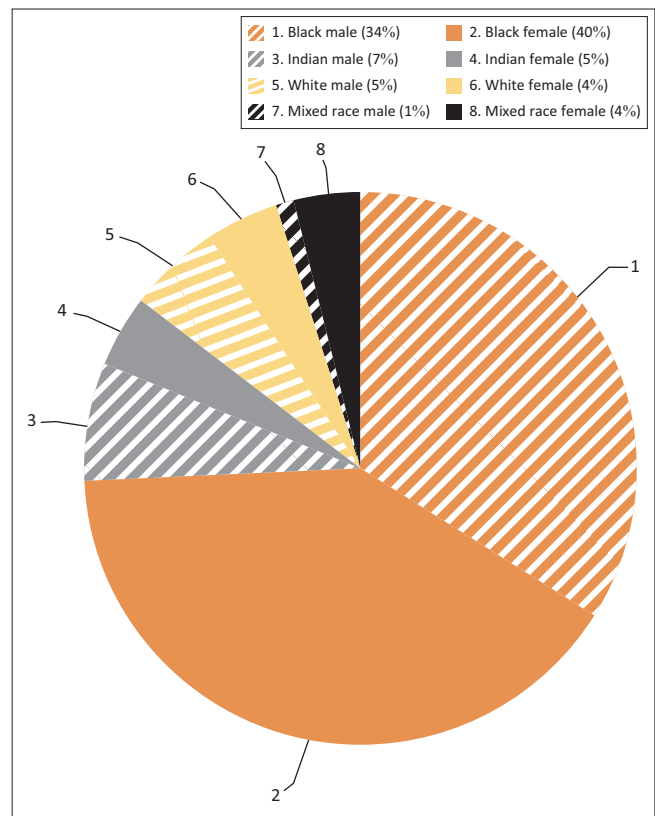
Figure 1 provides the distribution of race and gender. The 206 KC patients who were included in the analysis were made up of the four main ethnic groups in South Africa, namely, black people (74%), Indian (12%), white people (9%) and mixed race (5%). Fifty-three per cent of this sample were female.

The average age was  $24.0 \pm 8.53$  and  $22.9 \pm 7.46$  years for males and females, respectively. Some of the data on age

**TABLE 1:** Grading of keratoconus according to the Collaborative Longitudinal Evaluation of Keratoconus<sup>13</sup> method

Severity	Keratometry measurement
Mild	$K_{\text{steepest}} < 45 \text{ D}$
Moderate	$45 < K_{\text{steepest}} < 52 \text{ D}$
Severe	$K_{\text{steepest}} > 52 \text{ D}$

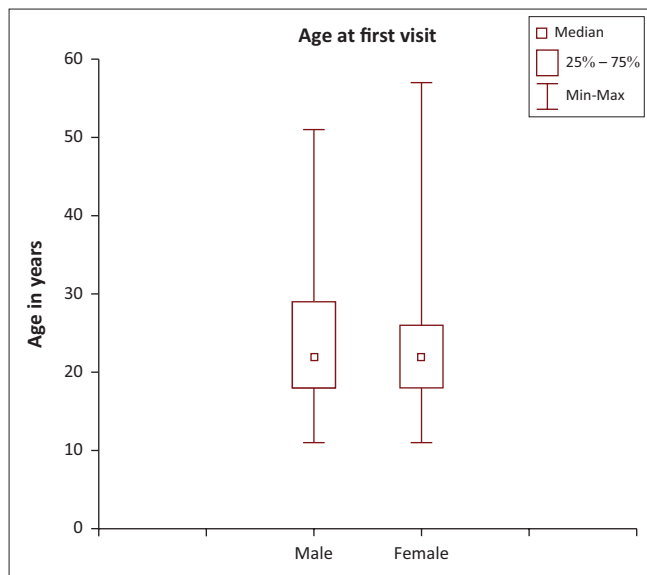
$K_{\text{steepest}}$ , keratometry measurement of the steepest meridian.



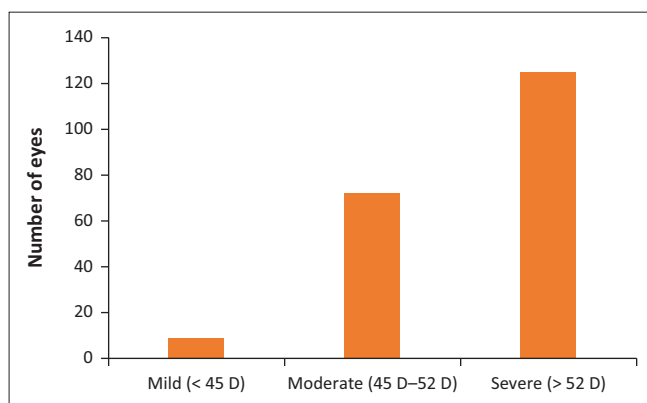
**FIGURE 1:** Pie graph representing the distribution of race and gender of the 206 keratoconus patients at the University of Johannesburg contact lens clinic over the period January 2007 to December 2017. Only patients with at least one good quality Pentacam scan were included in the sample.

were not normally distributed; therefore, medians and interquartile ranges were calculated as well. The box and whisker plot in Figure 2 provides the medians and interquartile ranges for the ages at first visit for male and female KC patients. The median and minimum ages were 22 and 11 years, respectively, for both males and females. The maximum age was 51 years for males and 57 years for females. The large variation seen in the whiskers of the plot is attributed to one 51-year-old male patient and one 57-year-old female patient. Otherwise most patients in the samples were in their twenties.

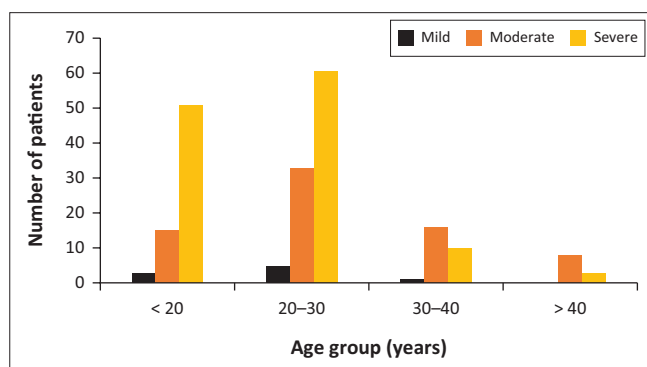
Of the 206 KC patients analysed, 61% were graded as severe, 35% as moderate and 4% as mild at first visit, as demonstrated in Figure 3. In cases where there were data available for both eyes the patient was graded according to the worse eye. Figure 4 shows the grading of KC with respect to the age groups. The majority of patients who presented at the clinic in the first and second decade of life were already in the severe stages of the disease, while the majority of patients in the third decade of life or older were in the moderate stages of the disease at first visit.



**FIGURE 2:** Box and whisker plots for the age at first visit for 97 males and 109 females. Medians, interquartile ranges and minimum and maximum ages are given. According to the Student t-test there was no significant difference in age between male and female patients ( $p > 0.05$ ).



**FIGURE 3:** Bar graph indicating the severity of keratoconus for 206 patients at the University of Johannesburg contact lens clinic, seen between 2007 and 2017.



**FIGURE 4:** Bar graph indicating the severity of the 206 keratoconus patients seen at the University of Johannesburg contact lens clinic with respect to age groups.

## Discussion

Black South Africans predominately inhabit the Johannesburg city centre and the surrounding suburbs near the clinic. An Indian community is also in close proximity to the university clinic. It may therefore be expected that the majority of our

patients would be made up of these two racial groups. Other than location being a factor for this study there are other international studies that suggest that the prevalence of KC is higher in non-Caucasian samples.<sup>18,19</sup> Georgiou et al.<sup>19</sup> investigated both Caucasian and Asian patients from the same area in the United Kingdom and found a higher prevalence of KC in Asian patients, thereby suggesting that ethnicity does play a role in the disease.

The sample in this study reflected a slightly higher number of females than males similar to that found by Toprak et al.<sup>20</sup> Other studies suggest that there is a preponderance of males affected with KC.<sup>5,6</sup> A recent study by Althomali et al.<sup>21</sup> concluded that there was no significant difference between genders with respect to disease predisposition. Romero-Jiménez et al.<sup>2</sup> proposed in their review of the literature on KC that it is still unclear whether KC significantly affects one sex more than the other.

Keratoconus is known to have its onset in the pubescent years; however, the age of onset versus the age of detection is often disparate. This could probably be explained by the asymmetric nature of the disease where KC progresses at different rates between the two eyes; therefore, patients may only notice a problem when the better eye starts to deteriorate. Medians were included in this study to express measures of central tendency because some of the data on age were not normally distributed. Patient ages ranged from 11 to 57 years of age at first visit, with the majority of patients presenting in the early second decade of life. This compares well with other studies conducted in Africa,<sup>16,22</sup> the Middle-East<sup>6</sup> and Asia.<sup>23,24</sup> Study cohorts from the United Kingdom,<sup>5</sup> the United States<sup>13</sup> and Australia<sup>15</sup> were older on average at the time of the respective studies. These patients presented between their late 20s to late 30s.

There are many methods to grade KC, some of which include the ABCD grading system,<sup>10</sup> the Keratoconus Severity Score (KSS),<sup>11</sup> the Amsler-Krumeich method<sup>12</sup> and the CLEK method.<sup>13</sup> There is no standardised method for grading KC, nor is there any method proven to be better than others.<sup>14</sup> The CLEK method is used frequently in the literature and was therefore the method of choice for this study. Keratoconic eyes were graded according to the keratometry measurement of the steepest meridian. Based on this grading system, it was found that most of the patients who presented at the clinic sought ocular care only when they had reached the severe stages of the disease. The University of Johannesburg clinic is a community clinic that predominately serves those patients who cannot afford private healthcare or medical aid. It is possible that these patients would spend money on an eye and vision test only if absolutely necessary (e.g. when the less severely affected eye starts to deteriorate). This could possibly explain why most of the patients at our clinic are already in the severe stage at first visit. Another possibility that adds to this burden is the lack of public healthcare facilities that are equipped to deal with KC. As mentioned above, KC begins

**TABLE 2:** Demographic summary of age in years and gender of patients.

Variable	Mild	Moderate	Severe
Age [median (range)]	24 (16–37)	23.5 (11–57)	20 (11–47)
Gender M/F %	1.5%/3%	18.5%/16.5%	27%/33.5%

Note: The one-way analysis of variance (ANOVA) test indicated that there was a statistically significant difference in age across the three severity groups ( $p < 0.05$ ).

in the pubescent years and progresses until the third or fourth decade of life at which point it starts to stabilise.<sup>5</sup> As can be seen in Figure 4 and Table 2, the trend in this sample appears to agree with the findings of Naderan et al.,<sup>6</sup> who suggested that the earlier KC manifests the greater the severity of the disease. The majority of patients in the first and second decade fall into the severe category, whereas most patients in the third and fourth decade or older fall into the moderate category.

One of the important limitations to this study is the relatively small and clinically biased sample from a university-based clinic that lacked equal representation of all South African ethnicities. Further research with larger samples is required to prove the hypothesis that KC is more prevalent in the non-Caucasian population. While this was a relatively small sample, it was still necessary to present this data as this is believed to be the first study of its kind to provide demographic information concerning patients with KC from South Africa. One should bear in mind that all conclusions drawn from this research relate specifically to the clinically biased sample extracted from a university-based clinic.

## Conclusion

This study, which represents the demographics of KC patients attending a university-based contact lens clinic in Johannesburg, is believed to be the first of its kind in South Africa. The cohort presented here shows that KC has a predisposition for the non-Caucasian population and is more severe in younger patients than in older patients. Historically, South Africa has been known for the low socio-economic status of the non-Caucasian communities. Uncorrected refractive error and blindness caused by conditions (such as KC), which are left untreated, add to this burden. This emphasises the need to establish greater awareness and diagnostic ability to identify KC early so that it can be managed effectively with interventions such as corneal cross-linking. Early diagnosis and intervention will greatly impact the quality of life for KC patients and it could have a positive impact on the socio-economic status of the country.

The Pentacam often does not trigger for severely affected corneas, and therefore not all the patients who attended the UJ contact lens clinic could be included in this analysis. Although this may be seen as a limitation, this study is merely the beginning of trying to understand the disease from a South African standpoint and it emphasises the necessity for further research into the epidemiology of KC not just in South Africa but within Africa as a whole.

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## Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

## Authors' contributions

E.C. is the main author and researcher. A.R., DPhil supervisor, was responsible for the supervision and editing of the article.

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## Data availability statement

Data sharing is not applicable to this article.

## Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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