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Original Article

Quality of life of a sample of people with keratoconus in KSA

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الملخص

أهداف البحث: لترجمة استبانة بحث نتائج القرنية المخروطية واستخدامه لقياس وتقييم جودة حياة الأشخاص الذين يعيشون مع القرنية المخروطية في المملكة العربية السعودية.

طريقة البحث: تم إجراء مسح مقطعي عبر الإنترنت لمرضى القرنية المخروطية مأخوذا بأخذ عينات ملائمة من عدة مناطق في المملكة العربية السعودية. تم تحليل البيانات باستخدام التقنيات الكمية المناسبة.

النتائج: أكمل المسح واحد وتسعون مريضا من القرنية المخروطية (57,1% ذكور؛ متوسط الأعمار = 33,25 ± 6,72) مأخوذ من خمس مناطق في المملكة العربية السعودية. تم تشخيص ما يصل إلى 78.1٪ من الحالات عندما تراوحت أعمار المستجوبين بين 15 و 29 سنة. من بين 91 مشاركا ، أبلغ 11٪ و 27٪ و 30٪ عن عدم وجود تداخل معتدل ومتوسط في النشاط ، بينما أبلغ 17٪ و 15٪ عن وجود قيود كبيرة وقيود على النشاط ، على التوالي. فيما يتعلق بالأعراض، أبلغ 8٪ و 20٪ و 24٪ عن عدم وجود أعراض خفيفة ومتوسطة، بينما أبلغ 23٪ و 25٪ عن أعراض شديدة ومتطرفة على التوالي. أظهر البحث معاملات قوية وذات دلالة إحصائية بين الأعراض ومحدودية النشاط والعوامل الديموغرافية. أظهر تحليل الانحدار للعلاقة بين الأعراض/قيود النشاط والعوامل الديموغرافية أن حدة البصر فقط والعين المصابة بالقرنية المخروطية والمنطقة كانت ذات دلالة إحصائية عند 5٪. حدة البصر أثناء ارتداء النظارات أو العدسات، فإن احتمالات الحصول على درجة ضعيفة في جودة الحياة تكون أعلى في كل من العين اليمنى واليسرى بنسبة احتمالات تبلغ 23.85 (4.21 إلى 135.24) و 6.0 (1.12 إلى 32.12)، على التوالي. حدة البصر غير معروفة وترتبط بالاحتمالات المتزايدة لدرجات الإزعاج العالية بنسبة 4.69 (1.06 إلى 20.62) و 13.63 (2.74 إلى 67.74) ، على التوالي.

الاستنتاجات: يعاني المرضى من إعاقات كبيرة في حياتهم اليومية يمكن تخفيفها عن طريق معالجة حدة البصر لدى المريض، والعين مع القرنية المخروطية، ومتغيرات المنطقة.

الكلمات المفتاحية: استبانة بحث نتائج القرنية المخروطية؛ دراسة مقطعية؛ مرحلة القرنية المخروطية؛ حدة البصر المصححة؛ حدة البصر؛ جودة الحياة

Abstract

Objectives: This study sought to translate the Keratoconus Outcomes Research Questionnaire (KORQ) and using it to measure and evaluate the quality of life of a sample of people with keratoconus in KSA.

Methods: A cross-sectional online survey of patients with keratoconus, drawn by convenience sampling from across several regions of KSA, was conducted. The data were analysed with appropriate quantitative techniques.

Results: Ninety-one patients with keratoconus (57.1% men; mean age = 33.25 ± 6.72 years) from five regions of KSA completed the survey. A total of 78.1% of the cases were diagnosed when the respondents were 15–29 years of age. Of the 91 participants, 11%, 27%, and 30% reported no, mild, and moderate interference with activities, whereas 17% and 15% reported substantial activity limitations. Regarding symptoms, 8%, 20%, and 24% reported no, mild, and moderate symptoms, whereas 23% and 25% reported substantial and extreme symptoms, respectively. Pearson rank correlation analysis indicated strong and statistically significant coefficients among the coded scores for symptoms, activity limitations and demographic factors. Regression analysis of the relationship between the scores for symptoms/activity limitations and demographic factors indicated that only the scores for visual acuity, eye with keratoconus, and geographic region were statistically significant at 5%. Visual acuity while wearing glasses or lenses and the odds of having poor QoL score were higher in both the left and right eyes [23.85 (95% CI, 4.21 to 135.24) and 6.0 (95% CI, 1.12 to 32.12), respectively]. Unknown visual acuity is associated with greater odds of higher annoyance scores

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[4.69 (95% CI, 1.06 to 20.62) and 13.63 (95% CI, 2.74 to 67.74), respectively].

Conclusion: Patients experience substantial impairments in their daily lives that could potentially be mitigated by addressing visual acuity, specific (left, right or both) eyes with keratoconus, and regional variables.

Keywords: Corrected visual acuity; Cross-sectional study; Keratoconus outcomes research questionnaire (KORQ); Keratoconus stage; Quality of life; Visual acuity

Introduction

Keratoconus is an ectatic disorder characterised by progressive thinning, scarring, and anterior protrusion of the cornea, which result in irregular astigmatism, opacity, and impaired vision.[1–3] Although its causes remain unknown, it was initially believed to affect 1 in every 2000 people.[2,3] However, with advancements in diagnostic technologies, the incidence rates are now understood to be more acute. In a study of mandatory health insurance records of 4.4 million patients 10–40 years of age in the Netherlands, for example, Godefrooij et al. have estimated the prevalence of keratoconus to be 1 in 375 (95% CI).[2,4]

The cornea is normally elliptical in shape. It steepens gently towards the central corneal zone and almost completely flattens between the intermediate and the peripheral corneal zones, such that its curvature's radius varies evenly from the centre towards the periphery. In patients with keratoconus, the corneal apex often occurs in the lower region and is severely protruded, thus resulting in an uneven corneal shape.[2]

Because the disorder is progressive, the corneal shape and extent of astigmatism are usually mild at onset; consequently, early-stage keratoconus is correctable with either soft contact lenses or glasses. Although rigid gas-permeable (RGP) hard contact lenses are contraindicated, spherical hard contact lenses may be used, because they have an even structure and an evenly reducing radius of curvature towards the periphery.[2] The characteristically uneven corneal shape renders the use of hard contact lenses impractical as the disease advances, but aspherical and multi-curve hard contact lenses may still be used.[1,2]

Problem statement

Empirical evidence indicates that the prevalence of keratoconus in KSA is higher than that in other countries, possibly because of geographical/regional, environmental, and genetic differences, as well as differences in diagnostic technologies.[3–6] A 2018 paediatric survey in 522 patients (6–21 years of age) the estimated keratoconus prevalence was 4.79% (95% CI = 2.96–6.62).[5] Althomali et al. have retroactively screened a sample of 687 patients (353 women) who had undergone routine pre-operative evaluation at a facility in Taif in 2014–2015. The prevalence of keratoconus was 8.59%, and 6.55% and 2.04% had bilateral manifest keratoconus and unilateral manifest keratoconus, respectively. Furthermore, sub-clinical bilateral and unilateral keratoconus were found 9.46% and 6.55% of the sample, respectively.[6] Given the high incidence of keratoconus in KSA, on the basis of empirical evidence, and the scarcity of research on the disorder's socioeconomic burden, this study was aimed at estimating the economic and quality of life effects of keratoconus on patients in the KSA.

Aim

To measure and evaluate the quality of life of people living with keratoconus.

Objectives

i. To translate and validate an Arabic version of the Keratoconus Outcomes Research Questionnaire (KORQ).
ii. To determine the quality of life of a sample of patients with keratoconus in KSA
iii. To estimate the effects of keratoconus on quality of life in a sample of patients in KSA

Materials and Methods

Time horizon

This study used a cross-sectional design, and was conducted in the northern, southern, western, eastern, and middle regions of KSA between April and June of 2022.

Sampling

A sample of people diagnosed with keratoconus in one or both eyes was assembled through convenience sampling from various regions in KSA. The participants were recruited both directly and through optometric and ophthalmology clinics in the KSA. To recruit the participants directly, the researcher contacted clinics on the basis of convenience and identified additional clinics through snowball practitioner referrals across KSA. With permission and assistance from the clinics, the researcher circulated the study information sheet and an invitation to participation to keratoconus support groups on two social media platforms (Telegram and WhatsApp) through the group administrators. The group members had either been treated by the clinics or were actively supported by the practitioners. The researcher similarly requested access to patients under active treatment by the clinics, to whom information sheets and invitation sheets were similarly provided by email and/or in-person.

As in a study by Pinto et al., the inclusion criteria included patients over 18 years of age who had keratoconus diagnosis, and a history of keratoconus-associated penetrating keratoplasty. Because severe comorbid eye conditions substantially influence quality of life, patients with severe comorbid conditions, including severe retinal disorders with visual impairment, and uveitis history, were excluded. Similarly, respondents unable to understand the KORQ (in English or

Arabic), who had undergone eye surgery unrelated to keratoconus, and who had any other chronic or acute diseases were excluded.

Data collection and analysis methods

Demographic and clinical history data were collected with structured questionnaires. Data on the effects of keratoconus on the quality of life was gathered with the KORQ, which comprises three sections gathering data on demographics, visual acuity (18 questions), and keratoconus symptoms (18 questions). Each question is measured on a four-point ordinal scale, in which respondents were asked to assess the symptom or visual (dis)ability as 'not at all', 'a little', 'quite a lot', and 'a lot'. For the purposes of analysis, the responses were scored on an ordinal scale of 0–4.

The translation process closely followed the Beaton and Gjersing protocol, as cited by Pinto et al., and has high scientific accuracy and transcultural validity.[22] The researcher, who is a native Arabic speaker, translated the KORQ to Arabic. Two independent Arabic speakers translated the Arabic translation back into English, before the variations in the three versions of the KORQ were analysed and reconciled. Additionally, the researcher had the benefit of two patients recruited from one of the facilities on whom the KORQ was tested to ascertain that the questions could be understood. The questionnaires were administered in the form of online surveys. Appropriate descriptive and inferential statistics were computed in SPSS or other statistical data analysis programs. The descriptive tests included mean, median, standard deviation, frequency tables, and charts. The inferential analysis comprised correlation analysis, Pearson chi-square test, and log likelihood test. The tests were evaluated at a percentage level of significance.

Validity and reliability

To ensure construct validity and reliability, the researcher developed the data collection tools through a review of the empirical and theoretical literature. The resulting tools were pilot tested with a jury of five experts in the field of optometry and ophthalmology. The tools were modified on the basis of findings from the pilot study to ensure that they measured the required constructs accurately and reliably, and could be administered reliably and efficiently. The pilot study involved 12 respondents, who were then excluded from the sampling frame. The reliability of the tools was evaluated with the Cronbach alpha test.

Ethical considerations

The Institutional Review Board at Al Baha University approved the study. Standard safeguards, including informed consent, participant anonymisation, transparency, integrity, confidentiality, and physical/digital security were strictly observed.[7] The ethical approval reference is No. 1443-21-43110072.

Results

Demographics

A total of 91 responses (57.1% men), 82% of which came from the middle, western, and southern regions, were

Table 1: Demographic characteristics of the respondents.

Question	Category	Frequency	Percentage
What is your age?	20–24 years	12	13.2
	25–29 years	12	13.2
	30–34 years	29	31.9
	35–39 years	25	27.5
	40–44 years	6	6.6
	45–49 years	4	4.4
	50 or above	3	3.3
How long has it been since you were diagnosed with keratoconus?	Less than 5 years	25	27.5
	5–9 years	23	25.3
	10–14 years	22	24.2
	15–19 years	14	15.4
	20 or above	7	7.7
At what age were you diagnosed with keratoconus?	5 years or fewer	1	1.1
	5–9 years	2	2.2
	10–14 years	6	6.6
	15–19 years	21	23.1
	20–24 years	29	31.9
	25–29 years	21	23.1
	30 or above	11	12.1
Are you now receiving, or have you ever received, treatment for keratoconus?	Did not receive surgical treatment	39	42.9
	Corneal transplantation	26	28.6
	Scleral	21	23.1
	Intacs®	5	5.5
Do you have any other eye diseases? If so please specify?	None	80	87.9
	Dryness	6	6.6
	Amblyopia	3	3.3
	Cataract	1	1.1
	Allergy	1	1.1

Table 2: Impairment in daily activities.

Impairment on daily activities	Using stairs (%)	Avoiding obstacles in one's path (%)	Distant vision (%)	Seeing small objects from a distance (%)	Facial recognition (%)	Depth perception (%)	Performance of household chores (%)
Not at all	14.3	14.3	8.8	12.1	6.6	5.5	23.1
A little	34.1	30.8	19.8	20.9	31.9	27.5	30.8
Moderately	35.2	34.1	22.0	22.0	20.9	38.5	27.5
Quite a lot	11.0	17.6	23.1	19.8	19.8	14.3	13.2
Extremely	5.5	3.3	26.4	25.3	20.9	14.3	5.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

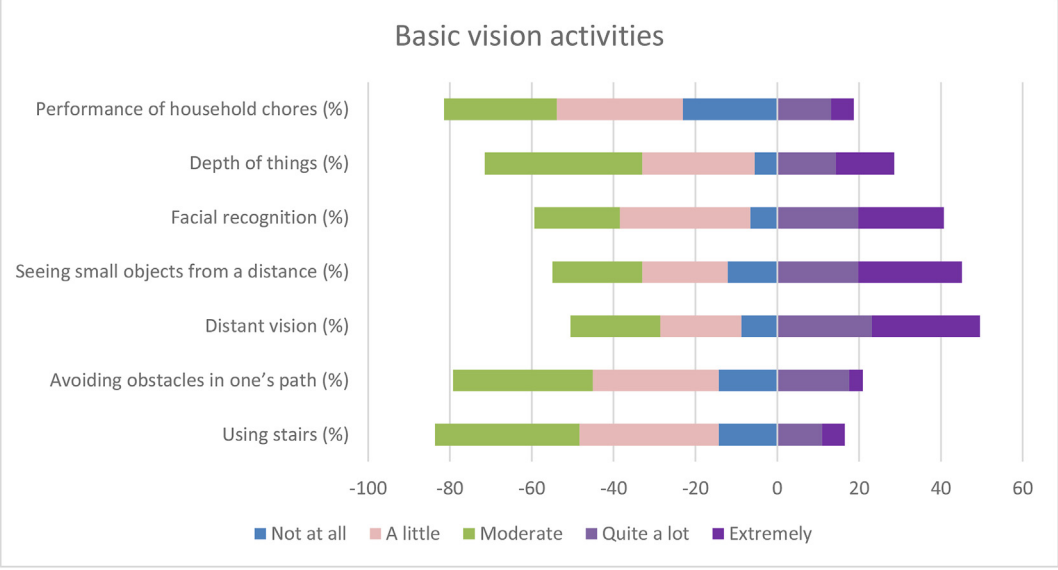

Figure 1: Basic daily activities. The bars below the zero measure 'not at all' and 'a little' scores.[11]

received. A total of 59% of respondents were 30–39 years of age, whereas 26.4% were 20–29 years of age (mean = 33.25; SD = 6.72). Eighty percent of the respondents had keratoconus in both eyes, and 73.1% of all cases were diagnosed when the respondents were 15–29 years of age. On average, respondents been diagnosed with keratoconus 10.10 years prior, and 7.7% had lived with the condition for more than 20 years. Nearly all patients were diagnosed with keratoconus 10–19 years prior. Notably, 12.1% of patients with keratoconus had comorbid eye conditions (Table 1).

A total of 42.9% of the respondents had not undergone any form of surgery to correct their condition, whereas 28.6%, 23.1%, and 5.5% had undergone corneal transplantation, had been prescribed scleral contact lenses, and had been treated with Intacs®, respectively. With or without surgery, all respondents except one who did not return a response, were using assistive technologies. Most patients used glasses (35.2%), scleral contact lenses (33.0%), or RGP lenses (26.4%), and 4.4% used a hybrid of assistive technologies. One respondent did not return a response (Figure 1).

For 80.2% of patients, keratoconus was diagnosed in both eyes, whereas for 8.8% and 11.0% of patients, the condition was diagnosed in the left and right eye, respectively. When respondents used glasses or contact lenses, their visual acuity exceeded 25% if keratoconus had been

Table 3: Visual impairment in different environmental conditions.

	Impaired vision on windy days	Impaired vision when tired	Bothered by vision in smoky environments	Impaired vision in dusty environments	Vision in low light
Not at all	11	6.7	5.5	4.4	9.9
A little	22	25.6	20.9	20.9	19.8
Moderate	28.6	23.3	24.2	16.5	22.0
Quite a lot	18.7	18.9	27.5	28.6	23.1
Extremely	19.8	25.6	22	29.7	25.3
Total	100	100	100	100	100.0

Table 4: Correlation analysis matrix. Note: ** and * denote significant correlation at the 0.01 level (two-tailed) and the 0.05 level (two-tailed), respectively.

	Day driving	Using stairs	Task performance	Glare sensitivity	Sun sensitivity	Annoyance with wearing glasses/lenses	Smoky environments	Dry day vision annoyance	Dusty day vision annoyance	Wearing hard contact lenses	Using glasses, lenses, etc.	Distant small object vision	Vision task impairment	Windy day vision	Vision while tired	Ability to work
Day driving	1.000	.600**	.461**	.215*	.523**	.237*	.317**	.454**	.385**	0.189	-.281**	.368**	.266*	.332**	.334**	.598**
Using stairs	.600**	1.000	.277**	0.163	.380**	0.157	.283**	.400**	.369**	0.170	-0.016	.314**	.286**	.333**	.222*	.468**
Task performance	.461**	.277**	1.000	.398**	.533**	.236*	.234*	.271**	.311**	0.021	-0.003	.525**	.255*	.261*	.261*	.428**
Glare sensitivity	.215*	0.163	.398**	1.000	.644**	.589**	.393**	.448**	.355**	.306**	-0.042	.494**	.350**	.410**	.553**	.261*
Sunny day sensitivity	.523**	.380**	.533**	.644**	1.000	.488**	.403**	.560**	.456**	.290**	-0.140	.438**	.395**	.390**	.575**	.418**
Annoyance with wearing glasses/lenses	.237*	0.157	.236*	.589**	.488**	1.000	.344**	.373**	.355**	.579**	0.068	.315**	.286**	.553**	.560**	.292**
Annoyance with smoky environments	.317**	.283**	.234*	.393**	.403**	.344**	1.000	.704**	.704**	.333**	-.256*	.230*	0.164	.505**	.600**	.345**
Dry day vision annoyance	.454**	.400**	.271**	.448**	.560**	.373**	.704**	1.000	.769**	.414**	-0.199	.283**	.309**	.680**	.816**	.476**
Day to day vision	.385**	.369**	.311**	.355**	.456**	.355**	.704**	.769**	1.000	.332**	-.366**	0.085	.219*	.710**	.689**	.318**

annoyance																
Annoyance with wearing hard contact lenses	0.189	0.170	0.021	.306**	.290**	.579**	.333**	.414**	.332**	1.000	-0.025	0.147	0.142	.410**	.410**	.274**
Using glasses, contact lenses, or other technology	-.281**	-0.016	-0.003	-0.042	-0.140	0.068	-.256*	-0.199	-.366**	-0.025	1.000	0.065	-0.033	-0.176	-0.111	-0.076
Distant small object vision	.368**	.314**	.525**	.494**	.438**	.315**	.230*	.283**	0.085	0.147	0.065	1.000	.577**	.231*	.250*	.523**
Vision task impairment	.266*	.286**	.255*	.350**	.395**	.286**	0.164	.309**	.219*	0.142	-0.033	.577**	1.000	.335**	.315**	.545**
Windy day vision	.332**	.333**	.261*	.410**	.390**	.553**	.505**	.680**	.710**	.410**	-0.176	.231*	.335**	1.000	.774**	.352**
Vision while tired	.334**	.222*	.261*	.553**	.575**	.560**	.600**	.816**	.689**	.410**	-0.111	.250*	.315**	.774**	1.000	.378**
Ability to work	.598**	.468**	.428**	.261*	.418**	.292**	.345**	.476**	.318**	.274**	-0.076	.523**	.545**	.352**	.378**	1.000
Night driving	.445**	.389**	.458**	.327**	.397**	.291**	0.146	.324**	0.143	0.201	0.015	.626**	.452**	.235*	.221*	.556**

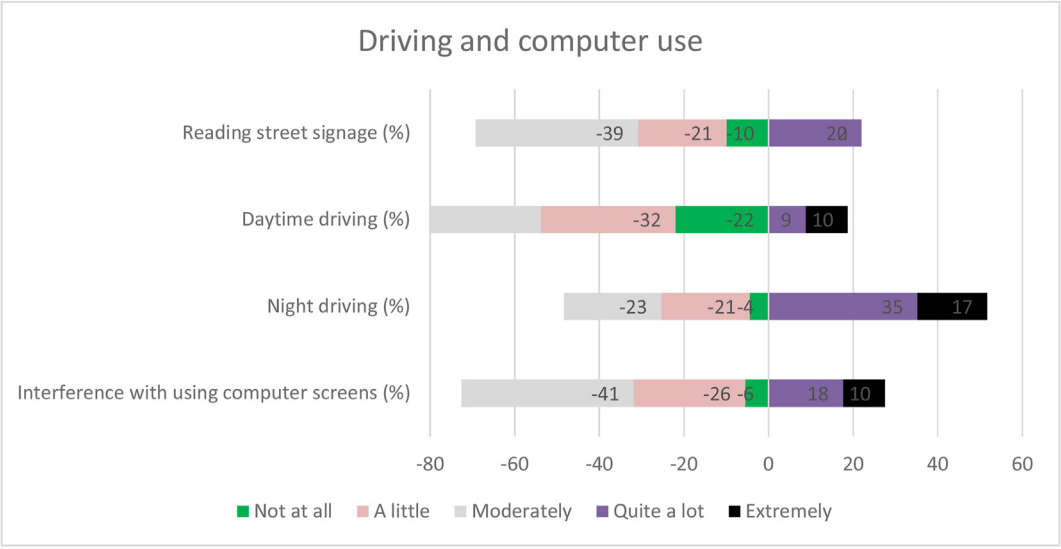

Figure 2: Driving and computer screen use impairment.

diagnosed in only the left or the right eye, but was only 18% when keratoconus had been diagnosed in both eyes. A total of 26.4% of respondents did not know their visual acuity when wearing glasses.

Activity limitations

Impairment in daily activities

Keratoconus impaired most patients' basic vision-associated life activities, e.g., going up/down stairs, avoiding obstacles in one's path, performing household chores, recognising faces, distant vision, seeing small objects in the distance, and determining the depth of objects in the environment (see Table 2). Overall, a minimum of 6.6% and maximum of 23.1% of the respondents reported not having any impairment in their daily activities. A total of 34.1% and 35.2% of the respondents indicated that they had either a little or moderate difficulty in using stairs, respectively, whereas 16.5% faced substantial or extreme difficulty. A total of 64.9% of respondents had some or moderate impairment in avoiding obstacles in their path, whereas 20.9% indicated that the impairment was either substantial or extreme. Distant vision was a moderate challenge to 41% of the respondents, and 49.5% indicated that the impairment was either substantial or extreme. An identical frequency distribution was observed for seeing small objects in the distance. Furthermore, 31.9%, 20.9%, 19.8%, and 20.9% indicated that they had a little, moderate, substantial, and extreme facial recognition impairment, respectively. A total of 66% had either little or moderate difficulty in determining the depth of things in their environment, whereas 28.6% faced more severe difficulties. Finally, 58.3% of the respondents faced little or moderate difficulty in performing household chores, whereas 18.7% faced more severe difficulties (Table 3).

Separation of 'not at all', 'a little' and 'moderate' scores (by assigning them a negative score) from 'quite a lot', and 'extremely' indicated that performing household chores and using stairs were least affected, followed by avoiding obstacles in one's path and judging depth, respectively. In contrast, distant vision, seeing small objects in the distance, and recognising faces had greater 'quite a lot' and 'extreme' scores (Figure 1).

Impairment in hobbies and leisure

Patients with keratoconus' leisure activities were equally impaired because of their sight. A total of 66% of the respondents indicated that they had some or moderate impairment in watching television, and 18.7% and 8.8% indicated that the difficulty was quite a lot and extreme, respectively. A total of 50.2% reported that their condition caused a little or moderate conflict with their hobby, whereas 22.0% and 12.1% indicated that the conflict with their hobby quite a lot and extreme, respectively.

Driving and computer use

At least 27% of respondents indicated that keratoconus severely affected their vision when using computer screens, but for 67% of the respondents, the interference was moderate. Compared with driving, the impairment in using computer screens was mostly moderate or less severe, whereas the effect on driving, particularly night driving, was mostly more than moderate. A total of 22% of respondents reported that their day driving was unimpaired, whereas only 4.4% reported unimpaired night driving. Furthermore, 20.9% and 23.1 believed that their day driving was impaired only a little and moderately, respectively, compared with 30.9% and 27.5%, for night driving.

A total of 51.7% respondents found night driving more than moderately impaired, compared with only 18.7% of respondents for day driving. Moreover, 9.9% of respondents had no difficulty in reading street signage, whereas 20.9%,

[1] The scores for all variables, except Region, Age, Gender, Keratoconus Diagnosis, Comorbid Conditions, Age of Diagnosis, Duration of KC, Treatment, Assistive Technology, Visual Acuity, and Eye with KC, were coded using an ordinal scale as follows: Not At All = 0; A Little =1; Moderate = 2; Quite a lot = 3; and Extremely = 4. The other variables either used an interval scale or a nominal scale.

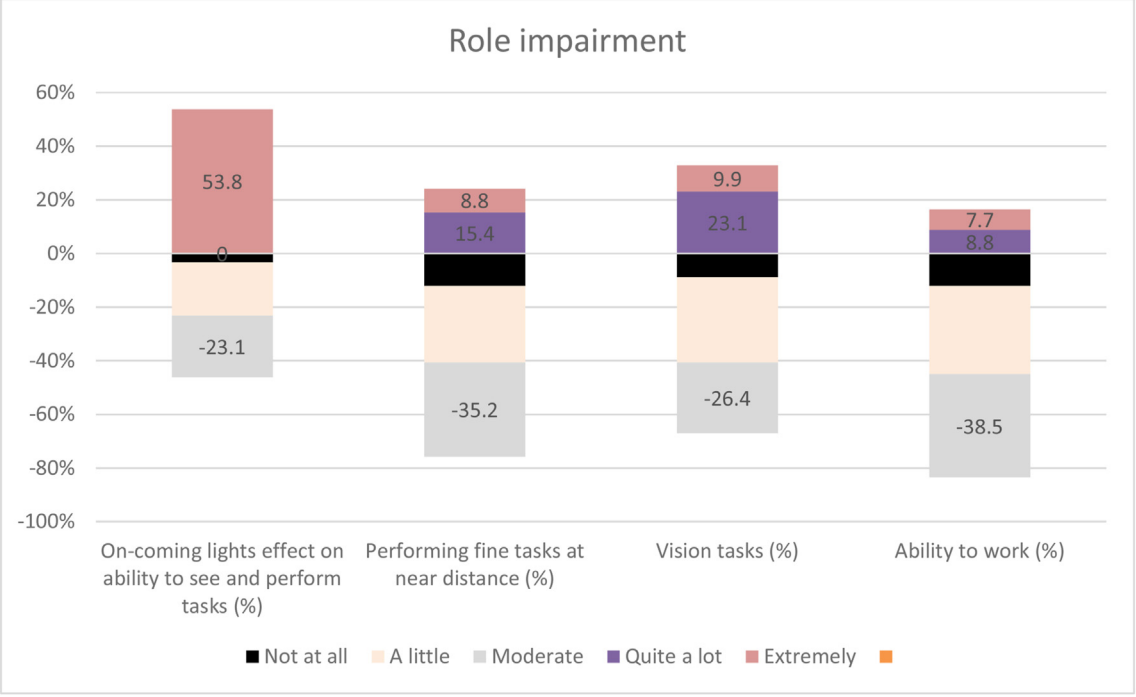

Figure 3: Interference in the ability to work.

38.5%, and 22% of respondents had little, moderate, and substantial difficulty, respectively (Figure 2).

Role-related impairment

A total of 33%, 38.5%, 8.8% and 7.7%% of the respondents had little, moderate, substantial, and extreme difficulty in doing their jobs, respectively, whereas the remaining 12.1% indicated that they had no difficulty. Oncoming lights interfered with the ability to see and perform tasks in 96.7% of respondents. A total of 53.8% reported that the resulting impairment was extreme. The effect on performing near distant tasks was less pronounced, with only 24.6% of respondents indicating that the impairment was either substantial or extreme, whereas 35.2% believed that the interference was moderate. With respect to performing vision tasks, less than 40.7% of respondents reporting having either little or no difficulty, whereas 26.4%, 23.1%, and 9.9% indicated that they experienced moderate, substantial, and severe difficulty, respectively (Figure 3).

Symptoms

Symptoms were present among most respondents. More than 76% of respondents described their distorted vision as either moderate or extreme, whereas 16.5% considered the disturbance as minor. Only 7.7% of respondents believed that glare sensitivity and wearing sunglasses was not bothersome, whereas 18.7% of respondents considered the disturbance to be minor. A total of 25%, 30%, and 19% of respondents believed that the bother from glare sensitivity and wearing sunglasses was moderate, substantial, and extreme, respectively. Although 8.8% of respondents were unbothered by bright sunny days in performing their tasks, 22%, 27.5%, 22%, and 19.8% believed the interference was minor, moderate, substantial, and extreme, respectively. A total of 25% of the respondents were either untroubled or only a little troubled by wearing rigid gas permeable contact lenses, whereas 42% believed that the annoyance was either quite a lot or extreme. Similarly, 38.6% of the respondents believed that annoyance due to headaches when wearing glasses/contacts was negligible, whereas 37% believed that the headaches were either substantial or extreme. A total of 20.9% of respondents believed that the headaches were only moderately troubling. Dry eyes did not trouble or only slightly troubled 26.4%, whereas 19.8%, 25.3%, and 28.6% of respondents believed the effect was moderate, quite a lot, and extreme, respectively (Figure 4).

The respondents' eyes and vision were similarly affected in poor environmental conditions. On windy days, 11% and 22% of respondents were not troubled or only a little troubled, respectively, whereas 28.6%, 18.6%, and 19.8% of respondents were moderately, quite a lot, and extremely troubled, respectively. A total of 32.3% of respondents were either untroubled or only a little troubled when tired, whereas 23.3%, 18.9%, and 25.6% were moderately, substantially, and extremely troubled, respectively. In poor lighting conditions, 9.9% of respondents had no difficulty, and 19.8% had a little difficulty. A total of 22%, 23.1%, and 25.3% faced moderate, substantial, and extreme difficulty, respectively. In smoky environments, 27.4% had little or no trouble, whereas 24.2%, 27.5%, and 22.0% faced moderate, substantial, and extreme trouble, respectively. Finally, in dusty conditions, 25.3% had little or no trouble, whereas 16.5%, 28.6%, and 29.7% faced moderate, substantial, and extreme difficulty, respectively (Table 3).

The vision impairment was least during windy days but progressively worsened when respondents were tired, in low light, in smoky environments, and ultimately in dusty environments (Figure 5).

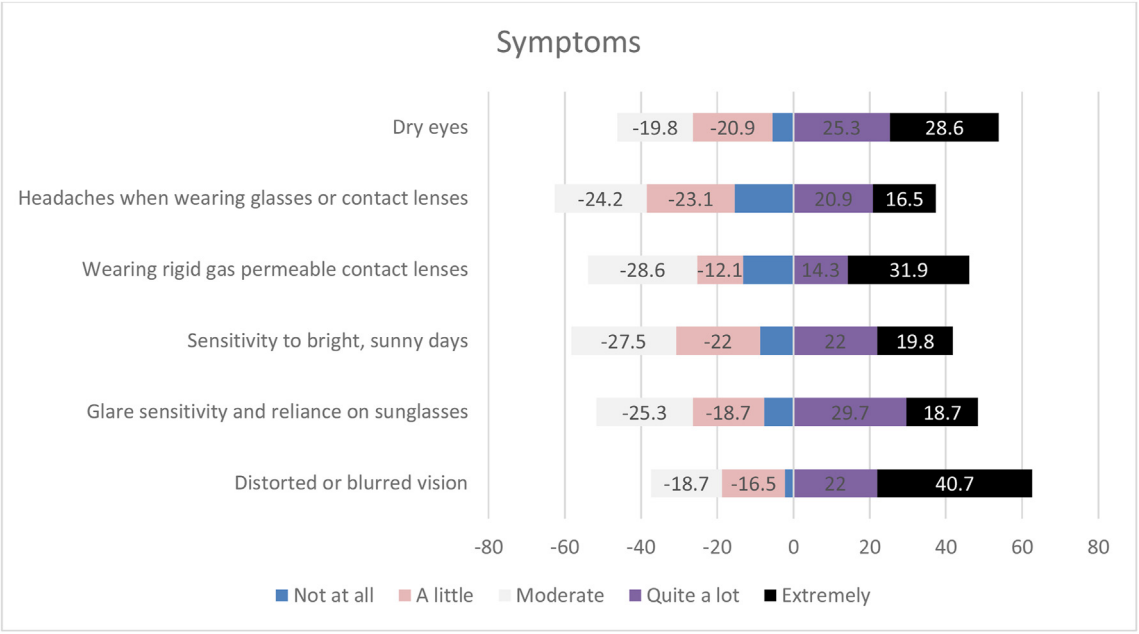

Figure 4: Mental, physical, and visual strain.

Correlation analysis

The correlation analysis indicated strong monotonic relationships among many variables (see Table 4), thus implying either causation or co-occurrence (see Figure 5). Against a null hypoyhesis that the correlation coeficient was zero, statistical significance implies that the resulting correlation coeficient is strong enough, given the size of the sample, to confidently ascertain that it is statistically different from zero.[2] The null hypothesis was rejected when the p-value was less or equal to the specified significance level. A statistically significant and positive correlation between age as well as annoyance scores with wearing either glasses or hard contact lenses and the duration of keratoconus was observed, at $p < 0.01$. One's gender (either male or female) has a statistically significant negative correlation with scores for annoyance due to vision in smoky environments, dry days, and windy days. Comorbid conditions showed a positive and statistically significant correlation with both the ability to see/perform tasks and the annoyance due to sensitivity to bright/sunny days. The remainder of the correlation coefficients (r) are shown in Table 4.

Regression analysis

Correlation does not indicate causation. Because quality of life was scored on an ordinal scale, ordinal regression analysis was performed to ascertain any associations between demographic factors and the quality-of-life scores (QoL scores). The QoL scores were averaged to create a composite QoL score. The QoL score was coded as 0 = not at all; 1 = a little; 2 = moderate; 3 = quite a lot; and 4 = extremely. Two further, similarly coded scores were created by averaging interference and symptoms separately. The demographic factors included age, age at diagnosis, whether treatment had been received for keratoconus, gender, visual acuity with eyewear, the existence of comorbid conditions, and region.

In the first model, the −2 log likelihood test indicated a significant improvement in the fit of the final model compared with the null model [$\chi 2(25) = 38.95$, $p < .05$]. The Pearson chi-square test [$\chi 2(315) = 360.68$, $p < .05$) and the deviance test [$\chi 2(315) = 167.58$, $p > 1.0$] were inconclusive regarding how well the model fit the data. Region and visual acuity in either the left or right eye when wearing glasses or contact lenses were statistically significant at 5%, implying that the improved scores were caused by the treatment effect and not sheer chance.[3] Regarding visual acuity while wearing glasses or lenses, the odds of having a poor QoL score were higher in both the left and right eyes, with an odds ratio of 23.85 (95% CI, 4.21 to 135.24), Wald $\chi^2(1) = 12.83$, $p < .05$ and 6.0 (95% CI, 1.12 to 32.12), Wald $\chi^2(1) = 4.37$, $p < .05$, respectively (Appendix A).

In the second model, the −2 log likelihood test showed a significant improvement in fit of the final model over the null model [$\chi 2(25) = 40.34$, $p < 0.05$]. The Pearson chi-square test [$\chi 2(315) = 306.62$, $p > .05$) and the deviance test [$\chi 2(315) = 194.94$, $p > 1.0$] indicated that the model fit the data. None of the scores for demographic factors, except region (Eastern), visual acuity with eyewear (unknown), and visual acuity with eyewear (left eye) were statistically

[2] The correlation coefficient ranges between −1 and 1, with 0 implying no correlation. The null hypothesis states that the observed coeficient of correlation resulted from sheer chance, thus when the p-value ≤ 0.05 (5%) or in some cases 1% and 10%, then it implies that observed coeficient can be reasonably considered to be different from zero.

[3] Both Region and Visual Acuity were coded using nominal scales. Regions were coded as follows: Western Region (1); Eastern Region (2); Middle Region (3); Southern Region (4); and Northern Region 5. On the other hand, Visual Acutiy was coded as Not Applicable (0); Left Eye (1); Right Eye (2); and Both Eyes (3).

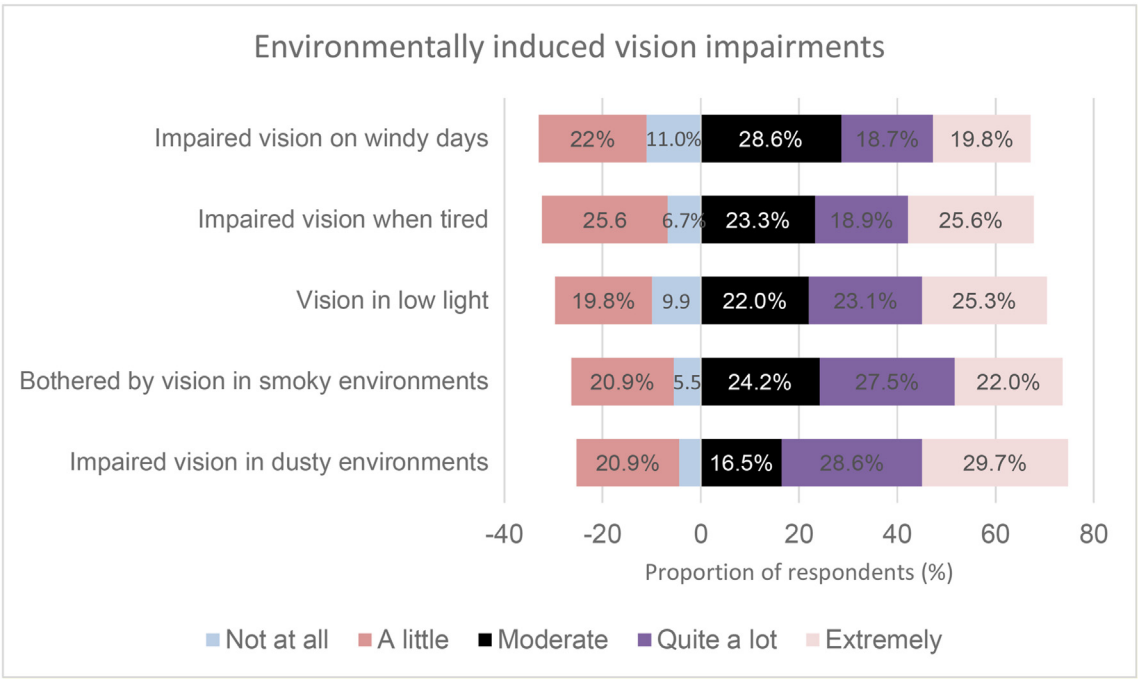

Figure 5: Vision impairment in diverse environmental conditions.

significant and positive coefficients. Accordingly, unknown visual acuity was associated with greater odds of higher annoyance scores [odds ratio of 4.69 (95% CI, 1.06 to 20.62), Wald $\chi^2(1) = 4.17$, $p < .05$ and 13.63 (95% CI, 2.74 to 67.74), Wald $\chi^2(1) = 10.19$, $p < .05$]. In contrast, the Eastern region had a negative likelihood of higher annoyance score, at a ratio of .03 (95% CI, 0 to .79), Wald $\chi^2(1) = 4.44$, $p < .05$ (Appendix B).

In the third model, the −2 log likelihood test indicated a significant improvement in fit of the final model over the null model [$\chi 2(25) = 41.42$, $p < .05$]. The Pearson chi-square test [$\chi 2(315) = 644.05$, $p < .05$) and the deviance test [$\chi 2(315) = 179.60$, $p > 1.0$] were inconclusive regarding the model's fit of the data. None of the demographic factors, except region (western and southern), eye in which keratoconus was diagnosed (right), and visual acuity with eyewear (left eye and right eye), were statistically significant and positive coefficients. Visual acuity in the left eye and right eye were associated with heightened odds of higher interference/difficulties, with an odds ratio of 32.71 (95% CI, 5.78 to 185.29), Wald $\chi^2(1) = 15.54$, $p < .05$ and 7.96 (95% CI, 1.53 to 41.45), Wald $\chi^2(1) = 6.06$, $p < .05$, respectively. Having keratoconus in the right eye decreased the odds of interference in vision, with an odds ratio of .09 (95% CI, .01 to .59), Wald $\chi^2(1) = 6.35$, $p < .05$. The same was true for the western and southern regions, with an odds ratio of .15 (95% CI, .03 to .85), Wald $\chi^2(1) = 4.57$, $p < .05$ and .09 (95% CI, .002 to .51), Wald $\chi^2(1) = 7.46$, $p < .05$, respectively (Appendix C).

Discussion

Although keratoconus is a low-prevalence disease that rarely results in blindness, its quality-of-life costs, particularly because it affects young adults and progresses through life,[4] are disproportionately higher than both its clinical severity and prevalence.[8,9] Even with acceptable visual acuity, patients with keratoconus show visual-related QoL scores comparable to those for advanced age-related macular degeneration.[10,11] This study evaluated a cross-sectional cohort of patients with keratoconus in KSA by using the KORQ tool.

Early onset, access, and type to care

Despite potential sampling bias, the results confirmed the disease's high incidence among children and young adults.[10,12] The findings indicated that 87% of those sampled were 10−39 years of age and that most were diagnosed with the condition before the age of 24 years, thus indicating substantial mounting deterioration in quality of life throughout the patients' lives.[13] The age at diagnosis and the post-diagnosis duration were likely to be a function of access to care rather than the actual disease onset.[14]

Furthermore, because all respondents reported using some assistive technology, whether the technologies in use and the other care that received were consistent with the severity of their condition was unclear. Glasses, soft lenses, and RGP lenses are indicated for early-stage keratoconus, whereas posterior keratoplasty and biomechanical cross-linking are indicated for advanced cases.[13,15,16] In this study, whether the treatments matched the progression of keratoconus and elicited substantial quality-of-life improvements was unclear.[16–19] Access to care, particularly early after diagnosis, is important, given that counselling and patient education are highly recommended to help patients avoid chronic habits, such as abnormal eye-rubbing, which hasten keratoconus progression.[13,20] The descriptive results also suggested that

using glasses or contact lenses was associated with higher visual acuity, particularly when keratoconus was diagnosed in only one eye.

Quality of life among patients with keratoconus

Activity limitations and symptoms

Even mild keratoconus may have significant effects on patients' visual functioning.[21] This study indicated that the symptoms ranged from negligible to moderate in 52% of the participants, and the remaining 48% reported more severe discomfort. Unlike past studies, such as Pinto et al.,[22] this study categorized the disease's interference with performing activities and symptoms, to help direct attention to specific disabilities and potential interventions. The most severe interference was observed for distance vision, seeing small objects in the distance, recognising faces, and judging depth. Night driving was the area with the most severe interference, and was followed by vision tasks and fine tasks at near distance. Arguably, these should be prioritised in any interventions.[23] Similarly, blurred vision, dry eyes, glare sensitivity, wearing RGP lenses, tiredness, low light, smoky environments, and dusty environments were associated with severe rather than moderate symptoms.

This study similarly indicated statistically significant correlations among the scores for activity interference and scores for symptoms, indicating co-occurrences and/or similar underlying factors. Day driving could be enhanced with interventions targeting glare sensitivity on sunny days, particularly because the correlations indicated that glasses/lenses enhanced driving, but annoyance existed regarding wearing either sunglasses or lenses.

Glare sensitivity intervention could similarly enhance vision-related task performance. Our findings indicated that dusty, dry, sunny, windy, and smoky environments, days, and conditions should be managed, because the resulting symptoms significantly correlated with most activity interference. Again, in this study, whether a failure to manage the symptoms resulted in the activity interference or whether the correlations indicated co-occurrence was unclear. In Gothwal et al., patients similarly reported that dusty conditions exacerbated keratoconus symptoms.[21] Occupational exposure should similarly be explored further. Some findings have suggested that employed and younger individuals exhibit more intense symptoms than unemployed and older individuals ($\beta = .44$; 95% CI, .17–.70; P = .001).[21] Heightened anxiety, annoyance, discomfort, and stress, particularly among young and active patients at the onset of keratoconus, pose serious mental health concerns.[10] Causation has been suggested by the high correlation coefficients between symptoms and activity interference but remains inconclusive.[24]

Regression analysis

The results indicated that known visual acuity in either eye (when wearing glasses) resulted in poorer QoL score outcomes, with more than twice the odds in the left eye than the right eye. These findings are consistent with previous findings linking vision-associated QoL scores to vision in the better eye.[9,11,22,25] Keratoconus progressively diminishes vision quality,[8,13] in agreement with findings that distance-corrected or binocular entrance visual acuity less than 20/40, corneal thinning to less than 460 μm in the better eye, and an average refractive cylinder of less than 2.5 dioptres, are associated with severe deterioration in all vision-associated QoL scores,[8–10] except ocular pain and general health.[8] All regions other than the northern region had higher odds of better QoL scores, and the eastern region had almost twice the odds of both the western and southern regions. Sampling bias might explain these variations, because eastern and northern territories were under-represented in the sample.[24] Incidentally, the second and third models also indicated that the coefficients of the eastern, western, and southern regions were statistically significant.

The finding that unknown visual acuity (with eyewear) is likely to result in more severe symptoms indicated that many participants had yet to receive appropriate or effective treatment or care. These results suggested that the care that the patients received and/or the assistive technology that had been prescribed worsened their keratoconus symptoms. Similarly, visual acuity in either the left or right eye, compared with that in both eyes, was associated with higher odds of activity interference. In contrast, having keratoconus in one eye only, particularly the right eye, was associated with lower odds of activity limitations. These findings are consistent with those from Pinto et al. indicating an association between better visual acuity and lower activity limitation, as well as symptoms.[22,25]

The high correlations among instrumental variables, as evidenced in the correlation analysis, hindered isolation of the effects of instrumental variables in this particular study; hence, more research with larger and more diverse samples is necessary to confirm the treatment effect. This aspect is particularly true for variables that were statistically significant at 10%, but not at 5%. At 10%, having keratoconus in only the left or right eye, and use of eyewear (glasses) was statistically significant. Using glasses was therefore associated with higher odds of having a better QoL score (i.e., less interference and symptoms), with an odds ratio of .06 (95% CI, .0 to 1.1), Wald $\chi^2(1) = 3.597$, $p < .058$. Having keratoconus in the left eye increased the odds of a poor QoL score, whereas having keratoconus in the right eye decreased the odds [odds ratio of 6.01 (95% CI, .71 to 50.55), Wald $\chi^2(1) = 2.73$, $p < .099$. and .19 (95% CI, .03 to 1.22), Wald $\chi^2(1) = 3.06$, $p < .08$, respectively]. Equally promising findings were observed with the second and third models, with respect to unknown visual acuity. Persons that indicated that they did not know their visual acuity presented with higher odds for activity interference and more severe keratoconus symptoms. The types of treatments received (cross-linking, corneal transplantation, and scleral lenses); eyewear (glasses); and the eye in which keratoconus is diagnosed were associated with lower odds of activity limitation and symptoms, p-value$<.1$ (Appendices B–D). In a prior study, for example, RGP lens use resulted in better general vision but increased ocular pain among patients with keratoconus in stages II–IV of the Amsler-Krumeich classification.[26]

Although this study did not include participants without keratoconus, past studies have shown that patients with

keratoconus have comparably poor vision-associated QoL relative to participants without keratoconus. In a study of vision-associated QoL, Aydin Kurna et al. and Tatematsu-Ogawa et al. have determined that wearing contact lenses result in higher corrected visual acuity, whereas patients with poor visual acuity in their better eye have equally lower distance vision, mental health, role difficulties, and social functioning.[27,28]

Similarly, whereas this study's regression findings with respect to some demographic factors, such as gender, were consistent with past evidence indicating that keratoconus does not show gender differences,[13,25] correlation results have indicated that gender might be relevant. For example, in a study of 574 patients, Gothwal et al. observed that keratoconus symptoms were 21% (95% CI, −.09 to −.59; $P < .001$)) worse among female than male patients.[21] Using the KORQ tool, Pinto et al. have also found lower function scores among men than women, and both function and symptom scores had a statistically significant association with the best-corrected visual acuity. Patients with a history of cross-linking treatment had better function scores and symptom scores that were statistically associated with best-corrected visual function.[9]

Conclusions

Despite its low prevalence, keratoconus has substantial costs regarding quality of life.[8,9,13] This study indicated that 32% of patients experienced more than moderate activity limitations, and 48% experienced more than moderate discomfort due to the symptoms. These findings are critical, given the young ages of the respondents. Diagnostic access and requisite care must be provided to those diagnosed with keratoconus to lessen the burden on their daily lives. Furthermore, additional studies are needed to confirm these findings and explore the insignificant regression results with respect to demographic factors that have been shown to be significant in past studies, e.g., gender and treatment type.[13,21] To the author's knowledge, this is the only study, other than Pinto et al., to use the validated KOQR tool, and the only one to do so in KSA.

Limitations

This study has several limitations. Beyond the relatively small sample size, the use of a convenience sampling strategy made the study vulnerable to high sampling error, selection bias, and generally lower robustness.[29] As such, this study's findings must be explored further in larger samples with more robust sampling approaches. This study's sample disproportionately included more male patients, although empirical evidence has indicated that keratoconus prevalence and/or the symptoms may be greater among female populations.[13,15]

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Conflict of interest

The authors have no conflict of interest to declare.

Ethical approval

Ethical approval was obtained from the institutional review board of Al Baha university (No. 1443-21-43110072) in 21-Mar-2022.

Authors' contribution

SKA testifies that she conceived, designed, and conducted the research, collected and analysed the data, and drafted and critically reviewed and approved the final draft of the manuscript. She is responsible for all aspects of the work. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jtumed.2023.03.008.

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