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## Article

# The Lifetime Expenditure in People with Keratoconus in Saudi Arabia

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**Abstract:** Aim: This study measures and evaluates the socioeconomic burden of people living with keratoconus in Saudi Arabia. Methods: The study employed a cross-sectional design, a Keratoconus Economic Burden Questionnaire, and a convenient sample of 89 keratoconus patients (58.4% male) drawn from multiple regions in Saudi Arabia. It was conducted using online surveys and the data was analysed using appropriate quantitative techniques. Results: The mean age and annual income of participants were 33.24 years and Saudi Riyal (SAR) 33,505.6180 (SD=62,215.29), respectively, with only 37% being employed for wages. Up to 94.4% needed glasses or contact lenses at least once a week and 73.0% received care from optometrists. The condition forced 45.9% of the respondents to change careers or leisure activities, with a further 51.3% having to take time off work. The mean annual out-of-pocket expenses for buying and maintaining glasses or contact lenses as well as traveling and accommodation for keratoconus-related treatment were SAR 8,673.19 (SD=11,307.73), with 48.32 incurring upwards of SAR 12,000 over the period. The treatment costs increased with disease duration,  $r(89) = .216, p < .05$ . Regression results show that the existence of comorbid eye disease, changing glasses at least once a year, and wearing either glasses or contact lenses at least once a week individually have statistically significant, negative effects on the total annual keratoconus treatment costs, while disease duration, utilisation of optometrists, and taking time off had a statistically significant increase on the total cost ( $p < .05$ ). Conclusion: With a prevalence rate of 1 in 375, progressive debilitation, and the lifetime nature of the disease, keratoconus is a critical public health concern in Saudi Arabia. The resulting visual impairment and discomfort as well as both direct and indirect economic burdens have considerable impacts on the patient's quality of life.

**Keywords:** keratoconus; lifetime expenditure; economic burden; keratoconus economic burden questionnaire

## 1. Introduction

Keratoconus is an ectatic disorder characterised by progressive thinning, scarring, and anteriorly protrusion of the cornea, which results in irregular astigmatism, opacity, and impaired vision [1-3]. While its causation remains unknown, it was initially thought to affect 1 in every 2000 people [2,3]. With the advancements in diagnostic technologies, however, the incidence rates are now known to be more acute [2]. In a study of mandatory health insurance records of 4.4 million patients aged 10-40 in the Netherlands, for example, Godefrooij et al. [4] estimated the prevalence of keratoconus at 1 in 375 (95% Confidence Interval (CI)).

Ordinarily, the cornea is elliptical. It steepens gently towards the central corneal zone and it nearly perfectly 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. This results in an uneven corneal shape [2].

As the disorder is progressive, the corneal shape and extent of astigmatism are usually mild at the onset, which is why early-stage keratoconus is correctable with either soft contact lenses or glasses. While rigid gas-permeable hard contact lenses are contra-indicated, spherical hard contact

lenses may be used as they have an even structure with an evenly reducing curvature radius 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*

The extant empirical evidence shows that the prevalence of keratoconus in Saudi Arabia is comparably higher than 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 involving 522 patients (aged 6 to 21) estimated keratoconus prevalence at 4.79% (95% CI=2.96-6.62) [5]. On their part, Althomali et al. [6] screened a sample of 687 patients (353 females) that had undergone routine pre-operative evaluation at a facility in Taif in 2014-2015. They found the prevalence of manifest keratoconus at 8.59%, with 6.55% and 2.04% having bilateral manifest keratoconus and unilateral manifest keratoconus, respectively. Further, the study found sub-clinical bilateral and unilateral keratoconus in 9.46% and 6.55% of the sample, respectively [6]. Given the high incidence of keratoconus in Saudi Arabia [4,6], at least from the available empirical evidence and a scarcity of research on the disorder's socioeconomic burden [4], the proposed study seeks to estimate its economic effects on patients in the Kingdom of Saudi Arabia.

#### *Aim*

To measure and evaluate the socioeconomic burden of people living with keratoconus

#### *Objectives*

1. To estimate the keratoconus-related lifetime expenditure in Saudi Arabia
2. To evaluate the socioeconomic burden on people with keratoconus and medical insurance
3. To provide a recommendation to overcome the economic burden on patients in Saudi Arabia

## **2. Methodology**

#### *Time Horizon*

This study relied on a cross-sectional design. A longitudinal design is not only resource- and time-intensive, it is unlikely to yield a comparably richer dataset than a cross-sectional design.

#### *Sampling*

The sample was drawn from various regions in Saudi Arabia. It comprised all people who have been diagnosed with keratoconus in one or both eyes that were asked to participate in the study. The study used convenience sampling. The participants were recruited both directly as well as through optometric and ophthalmology clinics in the Kingdom of Saudi Arabia.

#### *Data Collection and Analysis Methods*

Demographic and clinical history data were collected by way of structured questionnaires. Data on the effects of keratoconus on expenditures (including treatment and travel) was gathered using a keratoconus health expenditure checklist [1]. The questionnaires were administered in the form of online surveys. Appropriate descriptive and inferential statistics were computed by use of SPSS and other statistical data analysis applications.

#### *Validity and Reliability*

To ensure construct validity and reliability, the researcher developed the data collection tools through a review of the extant empirical and theoretical literature. The resulting tools were piloted using a jury of two experts in the field of optometry and ophthalmology. The findings from the pilot

study informed modifications to the tools to ensure they measure the required constructs accurately and reliably as well as ensure that they can be reliably and efficiently administered. The reliability of the tools was evaluated by way of the Cronbach Alpha test.

#### *Ethical Considerations*

The researcher sought approval from the Institutional Review Board at Al Baha University. Standard safeguards, including informed consent, participant anonymization, transparency, integrity, confidentiality, and physical/digital security were strictly observed [7].

### 3. Results

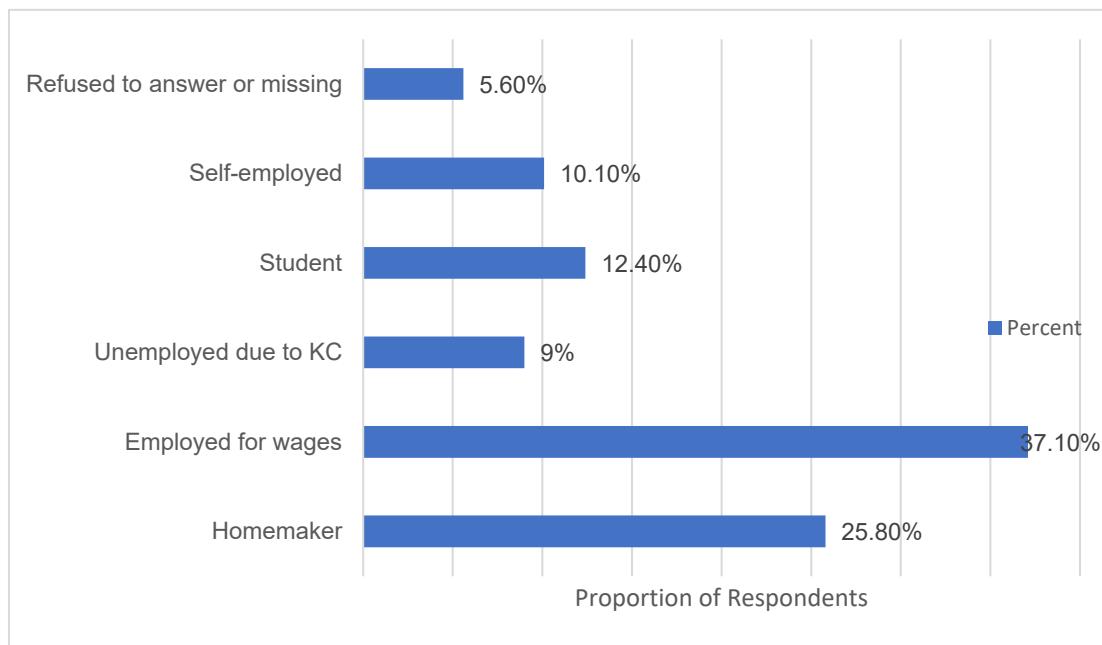
#### *Demographics*

Data was gathered between March and June 2022. A total of 89 complete questionnaires, from participants who had all been diagnosed with keratoconus, were received at the end of the data collection period. The average age of the respondents was 33.24 years (Standard Deviation (SD)=6.80). The average annual income was SAR 33,505.6180 (SD=62,215.29). Up to 46.07% of the respondents indicated that they had no income over the preceding 12 months. Table 1 summarises the participants' demographic attributes.

**Table 1.** Participants' demographics.

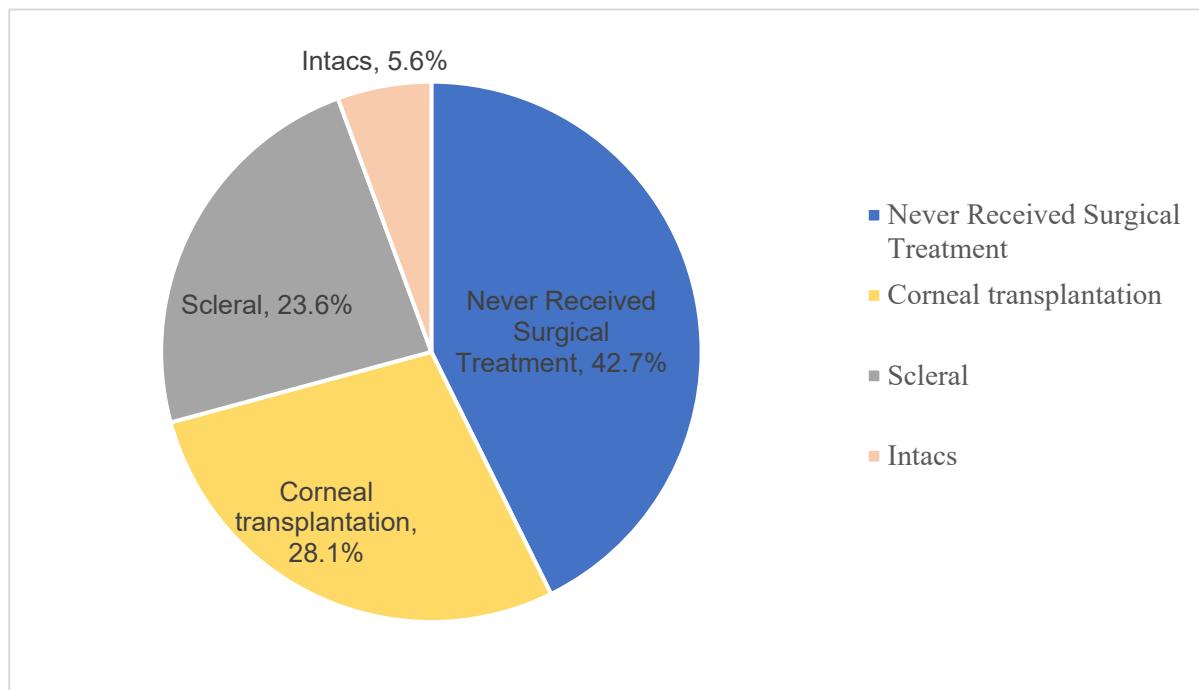
	Category	Frequency	Percent
<b>Gender</b>	Female	37	41.6%
	Male	52	58.4%
<b>Age</b>	Less than 24 years	12	13.5%
	25-29 years	12	13.5%
	30-34 years	28	31.5%
	35-39 years	26	29.2%
	40-44 years	6	6.7%
	45-49 years	4	4.5%
	Above 50 years	1	1.1%
	0	41	46.07%
<b>Annual income (SAR)</b>	5,000	5	5.62%
	10,000	9	10.11%
	20,000	9	10.11%
	50,000	7	7.87%
	100,000	7	7.87%
	More	11	12.36%

All respondents were diagnosed with keratoconus before their 20th birthday, with 55.1% and 41.6% of the respondents were diagnosed with keratoconus while aged 10-14 years and 15-19 years, respectively. Accordingly, it had been 5-14 years since 73% of the respondents were diagnosed with the condition. As many as 80.9% had keratoconus in both eyes, while 7.9% and 11.2% had keratoconus in the left and right eyes, respectively. Up to 12.4% of the respondents had a comorbid condition, including dryness, cataracts, and allergies. While 33% of the respondents did not buy any glasses at all over the preceding 12 months, 25.8% and 22.5% bought glasses once and twice over the same period, respectively. At least 14% reported buying glasses more than three times over the previous 12 months. Half of the respondents were either employed or self-employed, with as many as 9.5% reporting that they were unemployed on account of keratoconus. See Figure 1 below.



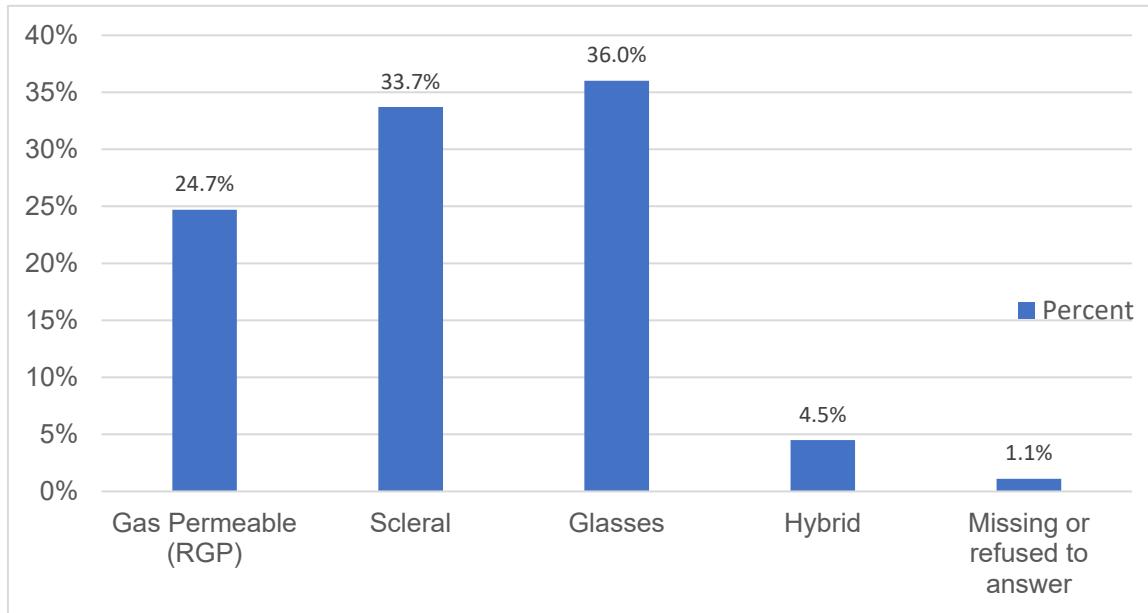
**Figure 1.** Participants' occupations.

Up to 42.7% of the respondents reported not having received surgical treatment for keratoconus, while 28.1% had undergone corneal transplantation. A further 23.6% and 5.6% wear scleral lenses and INTACS®, respectively. See Figure 2.



**Figure 2.** Keratoconus treatments received.

The results similarly indicate that 36.0%, 33.7%, and 24.7% of the respondents use glasses, scleral lenses, and rigid gas permeable lenses, respectively, while 4.5% used a hybrid of technologies. Of those who used glasses, contact lenses, or other assistive technologies, 56% reported normal visual acuity in either eye, while 18.2% had normal visual acuity in both eyes. At least 26% reported not knowing their visual acuity. See Figure 3.



**Figure 3.** Assistive technologies.

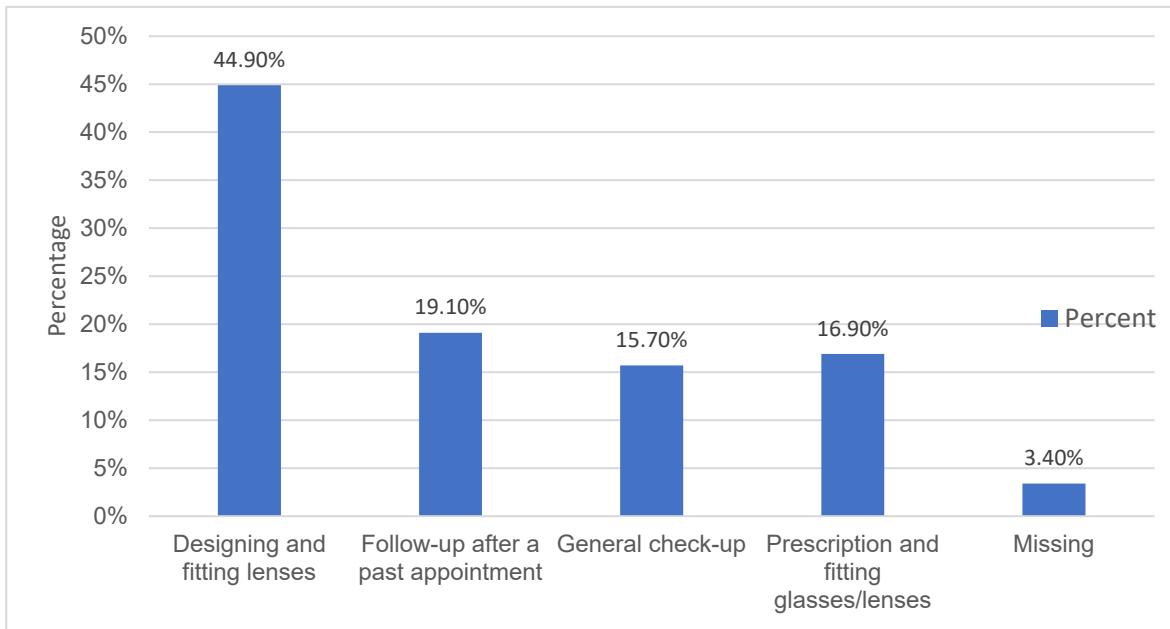
Only 5.6% reported never needing glasses or other assistive technologies to see well, with 11.5% and 82.8% reporting needing glasses once or twice a week and many times a week, respectively.

#### *KC-related disability and productivity losses*

The results indicate that 45.9% of the respondents were forced to change careers, jobs, leisure activities, and/or courses of study on account of keratoconus. A further 51.3% reported having had to take time off work or having been indisposed to work either because of their condition or need to receive treatment/care for keratoconus. The reasons for these changes included occupational disability (e.g., inability to cope with dusty work environments, failing mandated medical exams, and occupations or hobbies that require excellent vision), the necessity to seek adequate treatment, prolonged symptoms/discomfort (headaches, blurred vision, deterioration of vision in the day, and eye strain). See Appendix A. The resulting disability is such that 47% of the respondents were unable, at least once over the preceding twelve months, to care for themselves.

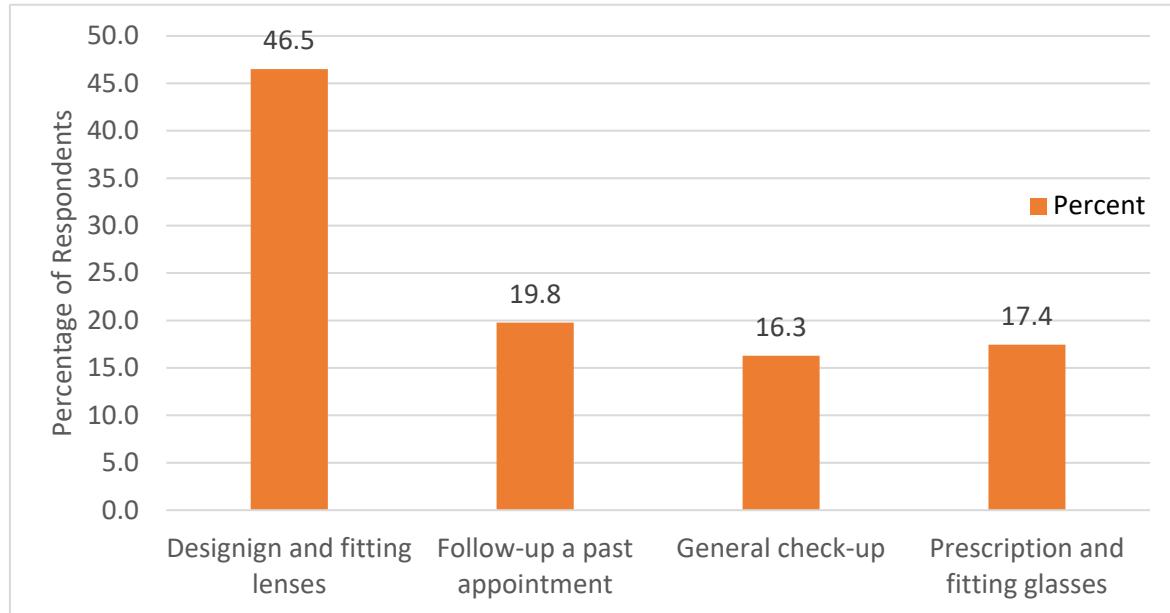
#### *Types of Care*

The majority of the respondents attended private clinics for keratoconus care (52.8%). Up to 73.0% of the respondents reported receiving care from optometrists, while 27% did not. Most of the services sought from non-optometrists include designing and fitting lenses. Figure 4 summarizes the results.



**Figure 4.** Optometric services sought.

At least 38.2% of the respondents sought care from other specialists, practitioners, and/or hospitals, either in addition to or instead of optometrists. The services sought are nearly identical to those sought from optometrists. See Figure 5.



**Figure 5.** Non-optometric services.

Only 37.1% of the respondents did not buy glasses in the preceding twelve months, with 25.8%, 22.5%, and 14.6% of the respondents reporting having bought glasses once, twice, and more than thrice in the past twelve months.

#### *Treatment Expenditure*

The mean out-of-pocket expenses and other expenses over the preceding year amounted to SAR 8,673.19 (SD=11,307.73). See Table 2.

**Table 2.** Out of pocket expenses.

	Min.	Max.	Mean	Std. Deviation
How much out-of-pocket expenses did you incur to buy glasses or contact lenses over the last 12 months?	0	7,500.00	3,045.64	2,058.31
How much money do you spend to take care of your contact lenses and glasses (e.g., wipes)?	0	10,000.00	1,473.64	1,895.54
How much, in out-of-pocket expenses, did you incur on transport and accommodation related to keratoconus surgery?	0	85,000.00	4,371.93	9,843.16

More than 51% of the respondents spent at least SAR 8,000 while 8.09% of the respondents incurred upwards of SAR 25,000 over the same period. See Table 3 below.

**Table 3.** Total KC-related medical expenses.

Total KC-related Medical Costs (SAR)	Frequency	Percent
0	2	2.25%
2000	13	14.61%
4000	11	12.36%
6000	11	12.36%
8000	9	10.11%
12000	14	15.73%
15000	5	5.62%
20000	9	10.11%
25000	7	7.87%
More	8	8.99%

On average, the cost of buying glasses and surgery-related transport/accommodation costs related to keratoconus surgery accounted for the largest cost drivers for the majority of the respondents. Buying glasses or contact lenses cost at least SAR 1,000 for 98.94% of the respondents over twelve months and more than SAR 5,000 for 17.46% of the respondents. See Table 4 below.

**Table 4.** Out-of-pocket expenses incurred to buy glasses or contact lenses over the last 12 months (SAR).

How much out-of-pocket expenses did you incur to buy glasses or contact lenses over the last 12 months (SAR)?	Frequency	Percent
0	1	1.16%
1000	17	19.77%
2000	19	22.09%
3000	17	19.77%
5000	17	19.77%
7000	11	12.79%
8000	4	4.65%

Additionally, Table 5 shows that 86% of the patients incurred more costs on supplies to maintain glasses, contact lenses, and other technologies. The maintenance costs ranged between SAR 250 and SAR 3,000 for 75% of the patients.

**Table 5.** Expenses on caring for contact lenses and glasses.

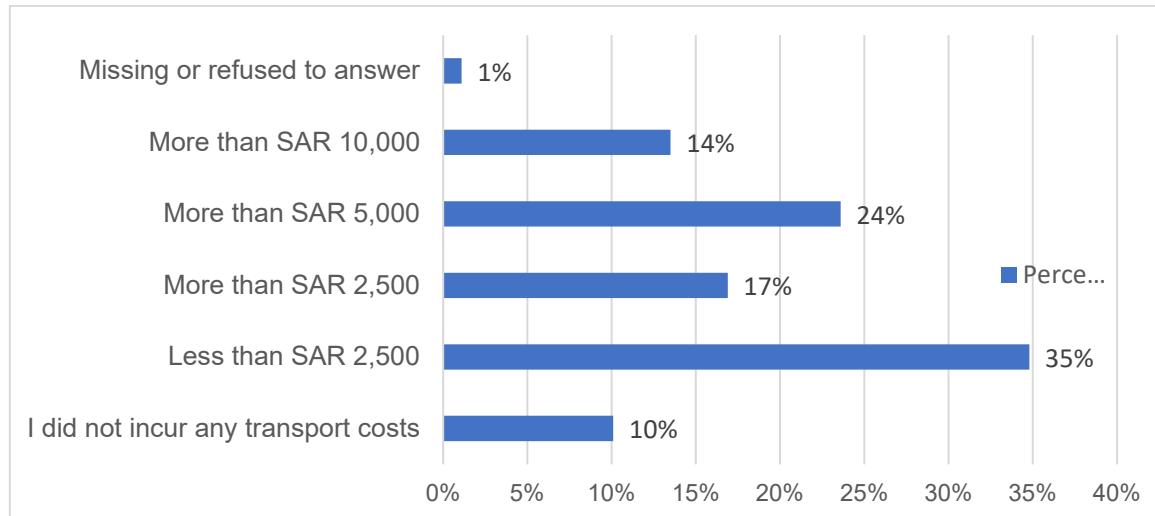
How much money do you spend to take care of your contact lenses and glasses (e.g., wipes)?	Frequency	Percent
0	12	13.48%
250	10	11.24%
500	20	22.47%
1000	17	19.10%
1500	8	8.99%
2000	4	4.49%
3000	8	8.99%
More	10	11.24%

While 30.68% of the respondents reported having spent nothing over the twelve months, 33% spent not less than SAR 3,000, and 14.76% incurred upwards of SAR 7,000 over the same period. See Table 6.

**Table 6.** Out-of-pocket expenses incurred on treatment over the past 12 months.

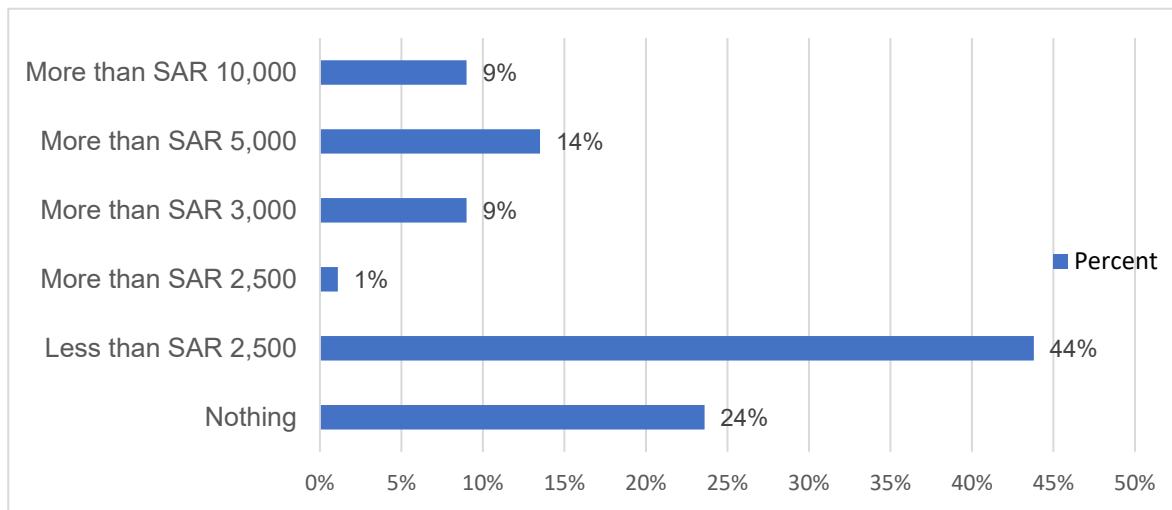
How much, in out-of-pocket expenses, did you incur on your treatment over the past 12 months?	Frequency	Percent
0	27	30.68%
1000	10	11.36%
3000	19	21.59%
5000	9	10.23%
7000	10	11.36%
10000	10	11.36%
More	3	3.41%

As shown in Figure 6, the out-of-pocket transport and accommodation costs related to keratoconus surgery ranged from zero to SAR 85,000, but the majority incurred less than SAR 3,000. Additionally, 89.9% of the patients incurred transport costs in visits to clinics for keratoconus care over one year. On average, 35.2% and 17.0% spent less than SAR 2,500 and SAR 5,000, respectively. A further, 13.6% spent upwards of SAR 10,000.



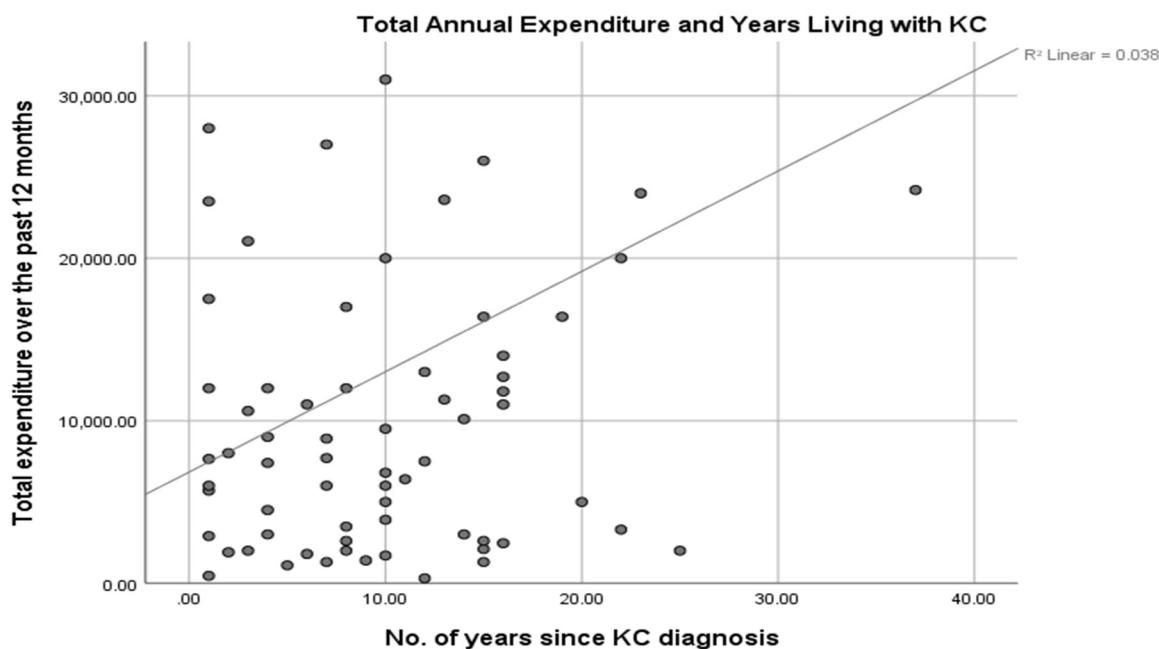
**Figure 6.** Non-surgery related costs.

Other than the costs of buying glasses, lenses, and supplies, the respondents incurred more costs, including costs for consultations, check-ups, testing, lens fitting, hospitalization, and surgical fees. The majority of the respondents spent less than SAR 2,500 over one year. See Figure 7 below.



**Figure 7.** Additional treatment costs.

On the whole, the line of best fit in Figure 8 shows that the annual expenditure tends to increase with the number of years living with keratoconus.



**Figure 8.** Annual expenditure increases with the number of years with KC.

Spearman's rho test shows the coefficient of correlation between the duration of disease and the total expenditure is positive and statistically significant,  $r(89) = .216$ ,  $p < .05$ . Similarly, there are multiple, statistically significant intercorrelations between multiple possible cost predictor variables, at five percent significance level. Notably, however, the coefficient of correlation of the frequency with which patients needed to wear glasses or contact lenses to see well and the existence of comorbid eye disease was negatively and statistically significant at 1 percent. The correlation coefficients summary is given in Table 7.

**Table 7.** Correlation analysis.

			Disease duration	Total Cost	Comorbid conditions	Frequency of wearing Glasses	Needed a carer	Frequency of buying glasses	Surgery	Using assistive technology	Treatment
<b>Disease duration</b>	Correlation Coefficient	1.000	.216*	-0.101	-0.005	0.091	0.073	.383**	-0.148	.264*	
	Sig. (2-tailed)		0.045	0.347	0.963	0.444	0.496	0.000	0.170	0.012	
<b>Total Cost</b>	Correlation Coefficient	.216*	1.000	-0.027	-0.040	.332**	0.035	0.100	-0.300**	-0.029	
	Sig. (2-tailed)	0.045		0.802	0.715	0.004	0.747	0.358	0.005	0.787	
<b>Comorbid conditions</b>	Correlation Coefficient	-0.101	-0.027	1.000	-.303**	0.114	-0.164	-0.068	0.187	0.057	
	Sig. (2-tailed)	0.347	0.802		0.004	0.337	0.124	0.525	0.081	0.598	
<b>Frequency of wearing Glasses</b>	Correlation Coefficient	-0.005	-0.040	-.303**	1.000	0.131	0.199	-0.138	-0.094	-0.019	
	Sig. (2-tailed)	0.963	0.715	0.004		0.278	0.064	0.201	0.386	0.860	
<b>Needed a carer</b>	Correlation Coefficient	0.091	.332**	0.114	0.131	1.000	-0.061	-0.124	-0.030	0.122	
	Sig. (2-tailed)	0.444	0.004	0.337	0.278		0.611	0.296	0.801	0.303	
<b>Frequency of buying glasses</b>	Correlation Coefficient	0.073	0.035	-0.164	0.199	-0.061	1.000	0.131	.222*	0.103	
	Sig. (2-tailed)	0.496	0.747	0.124	0.064	0.611		0.220	0.037	0.336	
<b>Surgery</b>	Correlation Coefficient	.383**	0.100	-0.068	-0.138	-0.124	0.131	1.000	0.081	.666**	
	Sig. (2-tailed)	0.000	0.358	0.525	0.201	0.296	0.220		0.451	0.000	
<b>Using assistive technology</b>	Correlation Coefficient	-0.148	-.300**	0.187	-0.094	-0.030	.222*	0.081	1.000	0.153	
	Sig. (2-tailed)	0.170	0.005	0.081	0.386	0.801	0.037	0.451		0.156	
	Sig. (2-tailed)	0.012	0.787	0.598	0.860	0.303	0.336	0.000		0.156	
<b>Treatment</b>	Correlation Coefficient	.264*	-0.029	0.057	-0.019	0.122	0.103	.666**	0.153	1.000	
	Sig. (2-tailed)	0.012	0.787	0.598	0.860	0.303	0.336	0.000		0.156	

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).

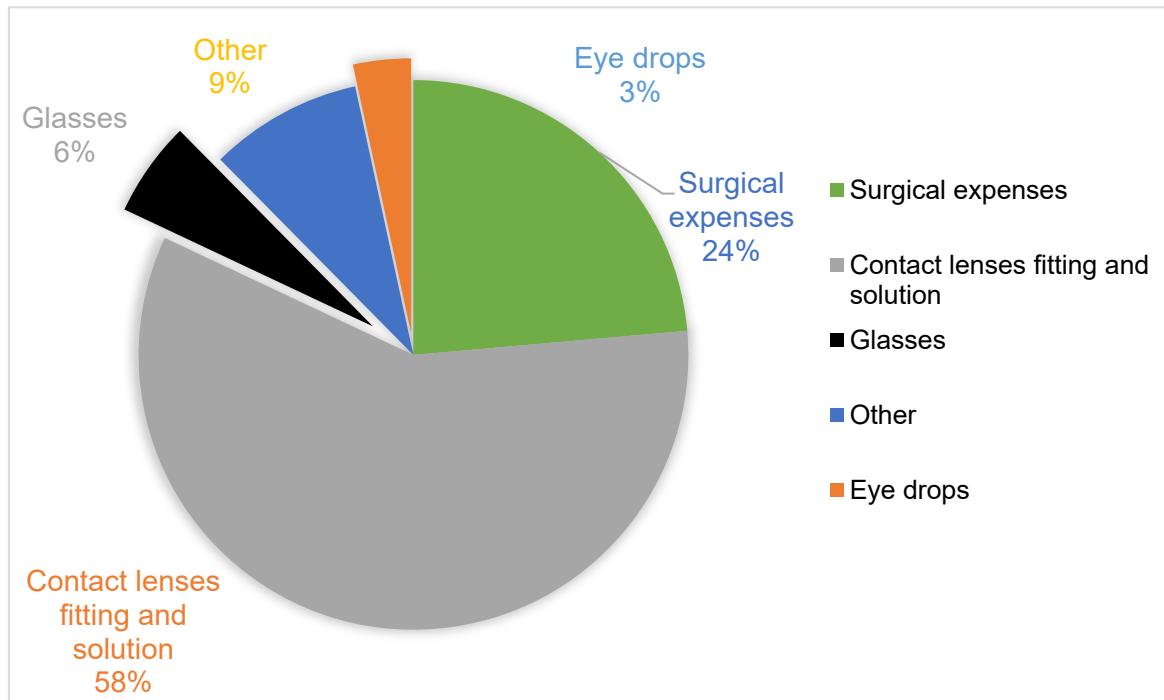
#### Insurance coverage

Table 8 shows that at least 42% of the keratoconus patients sampled did not have private insurance. Only 7.9% of the respondents indicated that keratoconus was covered under their private insurance policy. Up 87.6% did not individually pay for insurance premiums. The rest of the respondents paid premiums for private insurance premiums, which ranged between SAR 3,500 and SAR 10,000 for the majority of them. See Table 8 below.

**Table 8.** Private insurance premiums.

How much money do you pay as premiums for your private insurance cover per year (SAR)?	Frequency	Percent	Cumulative Percent
Nothing	78	87.6	87.6
More than SAR 3,500	7	7.9	95.5
More than SAR 5,000	2	2.2	97.8
More than SAR 10,000	2	2.2	100.0

More than 60% and 24% of the respondents believed that private insurance premiums were inaccessible and the cover offered poor value for money. At least 9% of the respondents believed a private insurance cover was unnecessary. Of the 48.3% who had private insurance, 92.96% were dissatisfied with the insurance rebates that they received to cover keratoconus treatment and other related care. They believed the rebates needed to cover more treatment and care expenses, including glasses, eye drops, and surgical expenses. See Figure 9 below.



**Figure 9.** Expenses that should be included in insurance rebates.

The correlation analysis does not, however, indicate causation. To ascertain whether the total cost can be predicted by any of the variables, linear regression models were developed. The resulting variables that predicted the total cost is as shown Table 9 below.

**Table 9.** Regression analysis.

Variable	Coefficient	Std. Error	t-Statistic	Prob.
Comorbid conditions	-3981.533	1479.328	-2.691448	0.0087
Frequency of buying glasses	-1808.047	1027.379	-1.759864	0.0825
Frequency of wearing glasses or lenses	-4944.126	1723.959	-2.867891	0.0053
Disease duration	3342.617	1345.000	2.485217	0.0151
Optometric care	5154.051	2503.182	2.058999	0.0429
Non-optometrist care	3882.983	2305.681	1.684094	0.0963
Time of work	5480.097	2359.953	2.322121	0.0229
Career change	2188.030	2439.605	0.896879	0.3726
Surgery	-2227.092	2562.879	-0.868981	0.3876
Needed carer	3369.768	2493.617	1.351358	0.1806
Type of clinic	2721.511	1882.408	1.445761	0.1524
R-squared	0.314568	Mean dependent var		8872.575
Adjusted R-squared	0.224379	S.D. dependent var		11323.79
S.E. of regression	9972.787	Akaike info criterion		21.37081
Sum squared residuals	7.56E+09	Schwarz criterion		21.68259
Log likelihood	-918.6301	Hannan-Quinn criteria.		21.49635
Durbin-Watson stat	2.064649			

The model could predict 31.46% of the variations in the total costs incurred in treatment, care, and lifestyle costs incurred on account of keratoconus. The existence of comorbid eye conditions significantly predicted inverse total cost scores,  $b = -3981.533$ ,  $t(87) = -2.69$ ,  $p < .01$ . Similarly, patients

who had to wear glasses or contact lenses to see well were likely to have lower costs than those that did not,  $b = -1808.047$ ,  $t(87) = -1.76$ ,  $p < .01$ . Undergoing surgery to correct keratoconus also has a negative effect on the lifestyle and medical costs of keratoconus, but this effect was not statistically significant,  $b = -2227.09$ ,  $t(87) = -0.87$ ,  $p > .05$ . On the contrary, disease duration, receiving care from optometrists, and taking time off had a statistically significant increase on the total cost of lifestyle and healthcare costs to the keratoconus patients. Other variables, including the inability to care for oneself, forced career or leisure activity change, receiving care from non-optometrists, and attending either a public or private clinic had a positive effect on the total costs but their effects were not statistically significant ( $p > .05$ ).

#### 4. Discussion

The income profile of the respondents shows that the sample mainly comprised a low-income population. Saudi Arabia's GDP per capita is estimated at USD 20,110 in 2022 [8], implying that only 36% of the sample that had more than SAR 50,000 fall in the average income category, while those with less or without income are either in the lower income brackets or were dependents. An estimated 42% of the respondents reported never having received surgical treatment for keratoconus, which given the fact that *corneal cross-linking* is arguably the most effective treatment for keratoconus [9–11], points to potentially poor access to the best care. This finding is consistent with past empirical evidence that cases of keratoconus in Saudi Arabia (and other countries in the region) are relatively more prevalent and advanced at the time of diagnosis than in other parts of the world[12].

While studies elsewhere in the world found broad variations in prevalence, they also thought that those were related to factors that include ethnicity, geography, diagnostic criteria, and methodological differences[13,14]. In respect to geographic factors, however, environmental factors such as ultraviolet light exposure and altitude may account for variations [13,15,16]. Generally, research shows high keratoconus prevalence in Saudi Arabia, Israel, and India compared to regions in North America, Europe, and parts of Asia [6,12]. Against an estimated global prevalence of 1 in every 2000 people for example, Assiri's study in Asiri province found that the prevalence of keratoconus have shown 20 per 100,000 population and high disease severity, with advanced stage keratoconus mean age of 17.7 (SD=3.6) years [12].

Further, the treatments received by participants in this study have lower levels of effectiveness, particularly concerning stemming the progression of the disease. The extant empirical evidence shows that INTACS® are ideally indicated for mild or moderate cases that are intolerant to contact lenses and have clear optical zones [14,17–19] They may be an alternative to rehabilitative lamellar or penetrating keratoplasty, as well as for uncorrected acuity[14,20,21]. Keratoconus is the main indication for scleral contact lenses for enhanced comfort, lens centration, and intolerance to corneal gas-permeable lenses[20] Empirical evidence shows it can prevent corneal transplantation in up to 80% of severe keratoconus cases, even with lamellar keratoplasty [14,20]. Keratoplasty is indicated in cases with corneal scarring and lamellar or full thickness [21].

While the cost, access, and availability of corneal donors remains an impediment to transplantation[22], the finding that up to 28% of the respondents had undergone corneal transplants encouraging but may be accounted for by sampling issues. Given the range of alternatives, differing effectiveness and indications, more research is needed to ascertain the effectiveness, access, and adverse effects of INTACS®, scleral lenses, and corneal transplants for treating keratoconus in Saudi Arabia against evidence-based indications, as a basis for enhanced efficiency and effectiveness in the management of the condition.

A higher-than-average proportion of the respondents in the present study attended optometric clinics, primarily for prescribing, designing, and fitting glasses or lenses, with about half as many seeking similar services from non-optometric practitioners/facilities. Surgery was not indicated as a reason for visits, even though 28% of the respondents had since undergone corneal transplantation. The proportion of those that had undergone surgery is lower than 48% in Chan et al., and it was unclear whether the surgery involved cross-linking procedures [1].

### *Keratoconus disability and productivity losses*

This study shows that keratoconus diagnosis occurs fairly early on in the lives of the patients, and thus the lifetime costs of the condition are likely to be cumulatively high. The age of diagnosis is consistent with small sample studies[23,24], but much lower than the estimated age-specific incidence of 1:7500 (13.3/100,000) established in large sample studies [4]. Godefrooij et al. [4], for example, determined that the average age of diagnosis is 28.3 years, but it is likely that the age of diagnosis as against the age of onset, depends on access to care[25]. Other than the age of diagnosis and the fact that keratoconus is not considered a disability in Saudi Arabia (other than in rare cases where patients' visual acuity is severely compromised), the results show severe symptoms of the condition and resulting occupational and social disability, as well as the financial consequences, are substantial. This may be exacerbated by the evidence of low awareness of keratoconus in the general population in Saudi Arabia, resulting in policy inaction, low health-seeking behaviour, and difficult social/work environments. Al-Dairi et al., for example, find that the prevalence of depression in a sample of keratoconus patients in Saudi Arabia was 40.6% ( $n = 134$ ;  $p < .001$ ) and further that the use of corrective lenses in both eyes heightened the risk of depression even higher [26].

The findings show that close to half of respondents are forced to take time off work or alter their career, leisure, educational, and even professional choices on account of keratoconus, which, potentially implies suboptimal decision-making with equally sub-optimal financial and economic implications. The results show an estimated 10% of the sampled population are completely incapable of working or finding work due to keratoconus. Godefrooij et al. estimated the twelve-month losses at AUD 500 for an Australian sample [4].

### *Keratoconus expenditure*

The calculated out-of-pocket costs for treating and managing keratoconus over twelve months, including the out-of-pocket expenses for glasses, contact lenses, and supplies, were SAR 8,673.19. Additionally, the majority of the keratoconus patients incurred SAR 2,500 to SAR 13,000 on transport, accommodation, and other ancillary expenses in seeking treatment. While this study did not verify the participants' incomes, if indeed 46% of those sampled had no income and 15.73% had an annual income of not more than SAR 8,673.19, keratoconus potentially has debilitating economic effects on the patients. Unlike Godefrooij et al. [4], this study's findings show that the expenditure is a positive function of the disease duration, possibly because the costs depend on the quality of treatment/care and whether or not such treatments stem the progression of the condition [27].

With glasses, the condition is correctable in the early stages but the failure to treat the underlying causal factors often fails to stem its progression [28]. Corneal collagen cross-linking can stop keratoconus progression, but it's often not covered by insurers despite leading to lower costs in the long term [1]. In a study to ascertain the cost-effectiveness of corneal collagen cross-linking in the USA, Canada, and Western Europe, Leung et al. [9], Salmon et al. [10], and Lindstrom et al. [11], established that patients who undergo corneal cross-linking enhance their quality of life, are less likely to require penetrating keratoplasty, and incur lower lifetime costs or productivity losses. They spend 27.9 fewer years in advanced keratoconus stages [11]. In Lindstrom et al.'s study, the direct medical costs for patients that underwent corneal collagen cross-linking were \$8,677 lower, i.e., \$30,994 compared to \$39,671. The per capita lifetime productivity gains associated with corneal cross-linking were estimated at \$43,759 [11].

Unlike Godefrooij et al. [4], Leung, et al. [9] and Rebenitsch et al. [24], this present study did not estimate the lifetime costs of the disease but focused on the individual cost drivers as predictors of the overall lifetime costs. This is arguably more practically relevant information for patients, practitioners, and policymakers. At 5% significance level, the regression results indicate that comorbid eye conditions, changing glasses frequently, and wearing glasses or contact lenses frequently are likely to result in lower lifestyle and medical costs of keratoconus. There are two possible explanations for this counter-intuitive finding. Past studies show that prescriptions to treat comorbid conditions and medication usage tends to be significantly higher among patients with some other eye conditions like dry eye disease. There is similarly a relationship between ocular

comorbidities and systemic diseases such as diabetes with implications for effective and efficient detection and management [9,27].

With a third of the sampled population in this study has not changed their glasses, it appears that the direct cost incurred in buying glasses is significantly lower than the indirect costs of either not wearing glasses or using poor glasses. Specifically, changing glasses once in twelve months and wearing either glasses or contact lenses at least once a week are likely to result in SAR 3,479.49 and SAR 10,429.30 lower annual total costs, respectively. On the contrary, a five-year disease duration is likely to result in SAR 5372.36. Patients who attended optometric clinics at least once in twelve months are likely to have SAR 10,759.03 more in total costs. The results are inconclusive on the cost impact of undergoing keratoconus surgery, attending either public or private clinics, and assisted living due to keratoconus. Thus, more research, with larger and more robust sampling is required to settle these findings.

Given the high hospital utilisation by keratoconus patients and the high cost of care, the lack of health insurance and/or government cover for the treatment and other costs has immense implications[1,9]. This study found that 73% sought optometric services over the preceding year, and close to 50% sought services from other services, which rates are comparable to higher utilisation rates elsewhere. Similarly, more research is required to investigate the impact of insurance cover on health services utilisation and health outcomes, including the age of diagnosis, health-seeking behaviour for patients with keratoconus, and the treatments open to them. While the actual costs are likely a function of income and lifestyle factors[1], this study's finding of comparatively higher average out-of-pocket expenditures relative to the less than SAR 5,000 paid by the majority of respondents in premiums shows a possible need for increased insurance coverage. This study identified an existing need for health insurance policies to cover fitting contact lenses and lens solutions, surgical expenses, and glasses.

#### *Type of care*

Keratoconus requires multi-disciplinary management, including primary eye care practitioners, general practitioners, ophthalmologists, and optometrists [11]. The condition is difficult to detect at early stages and it's usually possible to achieve good visual acuity with standard glasses, resulting in the unchecked progression of the disease. Studies into the sequence of events leading up to the keratoconus diagnosis show lack of awareness among patients and the criticality of referrals from primary points of contact to optometrists, ophthalmologists, and other specialists[29,30].

Collaboration is, however, little known and efforts are usually geared towards most prevalent eye diseases, age-related disorders, and primary care referral patterns[29]. Advanced stage keratoconus is difficult to correct and it's a common indicator of corneal surgery[9,10]. An estimated 20% of keratoconus patients require corneal transplantation [10]. This study shows acceptably high utilisation of both optometrists and other facilities, but there is a case to be made for the services offered by non-optometrists to increase from 38%. This is not least because the services sought from both optometrists and other practitioners appear to be the same when more differentiated services are possible. The potential for co-management and referral of cases across specialist/practitioner groups and from primary care to specialist care levels exists in the diagnosis and effective and efficient management of keratoconus[29].

## 5. Conclusions

An understanding of the financial burden of keratoconus in Saudi Arabia is important. The fact that a majority of the respondents in this study were diagnosed with keratoconus before their 20th birthday puts a clear emphasis on the lifetime economic burden, particularly given the lack of private insurance coverage. With just 5.6% of the respondents in this study reporting not using any assistive technology, the next line of inquiry should be on how well the technologies being used by keratoconus patients in Saudi Arabia are properly indicated given the severity of the symptoms and other clinical considerations, as well as the socioeconomic barriers to attaining evidence-based practice in respect to the same. Further research is similarly needed to ascertain the availability and

cost of cross-linking and other treatments that can stop the progression of keratoconus[9,11], including their comparative pharmaco-economic impact[11], the capacity of optometrists, hospitals, and other facilities to offer the same in Saudi Arabia. Like some past studies [4], this study's limitation flows from its small sample, potential selection bias, cross-sectional design, and the reliance on retrospective cost estimates. Longitudinal tracking of the expenses would be more productive in estimating the actual costs and projecting lifetime expenditures.

#### Appendix A: Keratoconus Outcomes Research Questionnaire (KORQ)

##### At what age were you diagnosed with keratoconus?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 5 years	1	1.1	1.1	1.1
	5-9 years	2	2.2	2.2	3.4
	10-14 years	37	41.6	41.6	44.9
	15-19 years	49	55.1	55.1	100.0
	Total	89	100.0	100.0	

##### In which eye were you diagnosed with KC?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Left eye	7	7.9	7.9	7.9
	Right eye	10	11.2	11.2	19.1
	Both eyes	72	80.9	80.9	100.0
	Total	89	100.0	100.0	

##### How long has it been since you were diagnosed with keratoconus

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 5	24	27.0	27.0	27.0
	5-9 years	23	25.8	25.8	52.8
	10-14 years	42	47.2	47.2	100.0
	Total	89	100.0	100.0	

##### How many times have you had to buy glasses in the past year?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Did not buy glasses last year	33	37.1	37.1	37.1
	Once in the past 12 months	23	25.8	25.8	62.9
	Twice in the past 12 months	20	22.5	22.5	85.4

More than thrice in the past 12 months	13	14.6	14.6	100.0
Total	89	100.0	100.0	

If you answered YES above, please explain why you needed to change
My office work because I am a military person and the lenses are affected by dust and dirt due to the nature of the work
Dust and dirt in the maintenance departments and open field work
I want to get a job so that I can get adequate treatment
All my hobbies need a strong look
Stay away from any work that requires focus and eye strain by looking continuously for long periods
Because of the inability to see well
I moved from one city to another because of driving
Lack of focus due to poor vision
Because it is difficult to practice the nature of work
Because of difficulty seeing and headache
Every time I apply for a job, I get a medical exam
Blurred vision and headache out of focus
Poor vision and deterioration while working during the day
Leaving work due to keratoconus
Difficulty seeing and not suitable for the job for my health condition
Because of the fear of recurring corneal injury
My job is tiring for my eyes
Entertainment stops to cover the costs of lenses and solutions
I can't see
I am a general chemistry graduate, and I was unable to apply for a laboratory preparation job, for fear of my eye
The cause of poor vision and deterioration of the cornea
Marine and violent sports as well as sports in the desert environment
Because of the light and the dust
Because of the glow and sunshine
Poor vision
Because of my lack of good vision, even with lenses, I had to choose a specialty that I didn't want to

## Correlations

		How long has it been since you were diagnosed with keratoconus	Total cost
How long has it been since you were diagnosed with keratoconus	Pearson Correlation	1	.214*
	Sig. (2-tailed)		.047
	N	89	87
Total cost	Pearson Correlation	.214*	1
	Sig. (2-tailed)	.047	
	N	87	87

\*. Correlation is significant at the 0.05 level (2-tailed).

1. Have you been diagnosed with keratoconus? \*

*Mark only one oval.*

Yes

No

#### Demographic information

2. At what age were you diagnosed with keratoconus?

3. In which eye was keratoconus diagnosed?

*Mark only one oval.*

Right

Left

Both eyes

## 4. Are you using glasses, contact lenses or other technology?

*Mark only one oval.*

- I use glasses
- I use soft contact lenses
- I use rigid contact lens (RGP)
- None

## 5. Are you now, or have you ever received treatment for keratoconus?

*Mark only one oval.*

- Yes
- No

## 6. What type of treatment did you receive?

*Mark only one oval.*

- Corneal Crosslinking
- Corneal Transplant Surgery
- Option 3
- Other: \_\_\_\_\_

## 7. What is your vision (visual acuity) with glasses/contact lenses (If known only)

*Mark only one oval.*

- Left eye
- Right eye

## 8. Your current glasses or contact lens prescription (If Known only)

*Mark only one oval.* Left eye Right eye

## 9. Do you suffer from any other eye diseases? if so please specify

*Mark only one oval.* No Other: \_\_\_\_\_

## 10. Email \*

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## 11. Address

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## 12. Phone number \*

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Keratoconus Outcomes Research Questionnaire (KORQ)

<https://docs.google.com/forms/u/0/d/1i3mZajVnCrcHpjP9XNKH2kK9s...>

## 13. Gender

*Mark only one oval.* Male Female

## 14. Date of birth

*Example: January 7, 2019***Appendix B: Saudi Arabia Keratoconus Economic Burden Questionnaire**

# Saudi Arabia Keratoconus Economic Burden Questionnaire

This form only seeks to gather information on the direct treatment and travel expenses that you incurred in relation to your keratoconus condition. It does not include any costs incurred on behalf of another person or treatment for a different condition.

---

\* Required

1. When were you diagnosed with keratoconus?

*Example: January 7, 2019*

2. How many times have you had to buy glasses in the past year?

*Mark only one oval.*

- I did NOT buy glasses last year
- 1 time
- 2 times
- More than 3 times

3. How frequently do you have to wear glasses or contact lenses in order to be able to see well?

*Mark only one oval.*

- Many times every day
- Once or so in a week
- I almost never need glasses
- Never

4. How much out-of-pocket expenses did you incur to buy glasses or contact lenses over the last 12 months?

---

5. How much money do you spend to take care of your contact lenses and glasses (e.g., wipes)

---

Private Insurance Costs

This section applies to expatriates and non-Saudis without access to Public Health Insurance.

6. Does your private insurance cover treatment related to keratoconus?

*Mark only one oval.*

Yes

No

I do not have private insurance

7. How much money do you pay as premiums for your private insurance cover per year (SAR)?

---

8. Are you happy with the rebates that you receive from your private insurance for treatment and other care related to your keratoconus condition? Please explain.

---

9. Do you think you would pay more in premiums to have an insurance policy that would give higher rebates for glasses/contacts and other care related to keratoconus?

*Mark only one oval.*

Yes

No

10. If you were not legally required to have private insurance, which of the following reasons explains why you would not buy a policy?

*Mark only one oval.*

I can manage without a private insurance cover

It is too expensive

It is bad value for money

Other: \_\_\_\_\_

11. In your opinion, which of the following expenses should be included in insurance rebates?

*Mark only one oval.*

Eye drops

Glasses

Surgical expenses

Contact lenses fitting and solution

Other: \_\_\_\_\_

**Expenses  
Managing  
Keratoconus**

This section covers any expenses that you have incurred in the past 12 months related to managing your keratoconus condition.

12. Did you receive care from an optometrist relating to your keratoconus condition over the past 12 months?

*Mark only one oval.*

Yes  
 No  
 Other: \_\_\_\_\_

13. What clinic did you attend for the keratoconus care?

*Mark only one oval.*

Government clinic or facility  
 Private clinic or facility  
 Not-for-profit clinic

14. What services did you receive from these clinics?

*Mark only one oval.*

Prescription for glasses  
 Lens design and fitting  
 General check-up  
 Follow-up after a past appointment  
 I was referred to the facility  
 Other: \_\_\_\_\_

15. How much did you incur in transport costs to visit a clinic for your keratoconus condition over the past 12 months (in SAR)?

---

16. What other treatment expenses did you incur for your keratoconus condition (do not include any costs buying glasses, contact lenses and lens solutions) including the costs for consultations, check-ups, testing, lens fitting, hospitalisation and surgical fees?

---

17. How much, in out-of-pocket expenses, did you incur on your treatment over the past 12 months?

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18. Other than the optometrists, did you receive keratoconus treatment or care from any other practitioners, specialists and/or hospital?

*Mark only one oval.*

Yes

No

19. What sort of eye clinics do you attend for treatment or care related to keratoconus?

*Mark only one oval.*

Public

Private or not-for-profit

I do not receive any additional care other than my optometrist

20. What was the nature of the care that you received from these practitioners or hospitals (other than optometrists)

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21. I was experiencing problems with my contact lenses

*Mark only one oval.*

I needed to fit contact lenses  
 Follow-up on a past appointment  
 Routine check-up  
 Prescription check for my glasses  
 Surgery  
 Other: \_\_\_\_\_

22. Have you undergone any surgery to treat keratoconus?

*Mark only one oval.*

Yes  
 No

23. If you underwent surgery to treat keratoconus, what type of surgery was it?

---

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24. How much, in out-of-pocket expenses, did you incur on transport and accomodation realted to the said surgery?

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25. How much, in out-of-pocket expenses, did you incur for the actual surgical consultations, prep, procedure and post-operative care (in SAR)? This excludes the cost of glasses, contact lenses and lens solutions.

---

26. Over the past twelve months, did you undergo therapy, support and/or other secondary care in relation to keratoconus?

*Mark only one oval.*

Yes  
 No

27. If Yes, what professionals did you receive care from?

*Mark only one oval.*

GP  
 Psychologist  
 Psychiatrist  
 Homeopath  
 Traditional Chinese Medicine  
 Masseur  
 Social support services  
 Personal care services  
 Other: \_\_\_\_\_

28. How much, in out-of-pocket expenses, did you spend on transport and accommodation for these visits?

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29. How much in, out-of-pocket expenses, did you spend for these services?

---

#### Informal Care and Support Costs

30. What do you do for a living?

*Mark only one oval.*

- Employed for wages
- Self-employed
- A homemaker
- A student
- Retired
- Unable to work because of keratoconus
- Other: \_\_\_\_\_

31. Have you ever had to change your career, job, leisure activity and/or course of study because of keratoconus? \*

*Mark only one oval.*

- Yes
- No

32. If you answered YES above, please explain why you needed to change

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33. How much do you, your spouse and any other persons living with you earn in the past one year?

---

34. In the past 12 months, did you have to take time off work or otherwise was unable to work because of your keratoconus or because you had to receive treatment/care for keratoconus?

*Mark only one oval.*

Yes  
 No

35. How much money, do you think you lost as a result of your inability to work or need to take time off to receive treatment/care (in SAR)?

---

36. Over the past 12 months, were there times that you were unable to care for yourself or otherwise needed a helper to care for you because of keratoconus?

*Mark only one oval.*

Yes  
 No

37. How much did you pay or spend for the carer or assistive technology (including tips, wages, and transport, etc.)

---

38. How much did you spend on the following medications over the past 12 months?

*Mark only one oval.*

- Prescription medicines, tablets, eye drops, etc.
- keratoconus? etc.
- Products: e.g. Low vision device, magnifier, cane,
- Equipment: e.g. Special television or computer
- screen, special computer software and telephone modifications
- Other: \_\_\_\_\_

39. Please provide a list of the medications, equipment, and other items that you bought over the past 12 months. Where possible, provide the cost.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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40. How much did you spend on the following medications over the past 12 months?

*Mark only one oval.*

Prescription medicines, tablets, eye drops, etc.  
 keratoconus? etc.  
 Products: e.g. Low vision device, magnifier, cane,  
 Equipment: e.g. Special television or computer  
 screen, special computer software and telephone modifications  
 Other: \_\_\_\_\_

41. Please provide a list of the medications, equipment, and other items that you bought over the past 12 months. Where possible, provide the cost.

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