

# *Keratoconus Awareness and Disease Effect on Life of Keratoconus Libyan Patients*

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**Abstract – Background:** Keratoconus, a progressive corneal thinning causing vision problems, disproportionately affects young adults during their formative years. Early detection and intervention are crucial for preventing vision loss and maintaining the quality of life. Assessing knowledge about the disease, treatment options, and family history is vital for effective screening programs targeting high-risk groups like those with positive family history and refractive errors. **Aim:** to test the overall awareness of keratoconus patients and their relatives about keratoconus. **Methodology:** A cross-sectional questionnaire with internal consistency assessed by a reliability coefficient of 0.8(Cronbach's alpha) was used to gather data from 83 participants (69 patients with keratoconus and 14 relatives). The questionnaire, administered through a mix of conventional interviews and online surveys, briefly explored awareness of keratoconus, its impact on quality of life, risk factors, knowledge, and patient feedback on surgical interventions. **Result:** 78% of keratoconus patients and 71% of their relatives were aware; there was a strong correlation between allergy and keratoconus; there was no correlation between awareness and either: age, gender, work nature, or academic level; 36% of keratoconus patients their lives were moderately affected, and 33% were severely affected by keratoconus; moreover, 18% were not satisfied with their surgery, 2% were satisfied, and 36% were delighted. **Conclusion:** Overall awareness of Keratoconus and their relatives was good; however, we need to increase this awareness, especially for the benefit of early detection and intervention that delay or stop disease progression, along with the role of positive family history.

**Keywords –** Keratoconus, awareness, screening program, subclinical keratoconus, Libyan patients, keratoconus effect on patients' life.

## I. INTRODUCTION

Keratoconus is a bilateral, asymmetrical, non-inflammatory corneal ectasia; however, recent research shows an inflammatory cytokine in the tear film, which indicates the presence of an inflammatory element. It is characterized by irregular thinning of the cornea with protrusion (bulging) that results in a cone-like corneal configuration, that leads to hazard change in the refractive error, myopia, and astigmatism (that is regular at first, then becomes irregular). Those refractive changes have a detrimental impact on the patient's vision, secondary to coma aberration, where keratoconus patients usually suffer from blurred vision, distortion of the image, glare, and other visual impairments. [1],[2].

The etiology remains unclear; however, many studies show a genetic predisposition with positive family history and some chromosomal abnormalities such as Down syndrome and Leber congenital amaurosis; moreover, repeated minor mechanical trauma shows a strong association with frequent eye rubbing secondary to eye allergy; wearing of hard rigid contact lenses, especially in predisposing people as that with positive family history; also; the sex hormone showing a contributing factor with risk of rapid change in keratoconus nature during pregnancy. [1]; [3].

The signs of keratoconus are that the eye's vision changes when you wear glasses with a normal retina. The best glasses for correcting vision are 6/6 (20/20) and have irregular astigmatism. You can also see small bumps on the cornea called Vogt striae, Fleischer rings around the base of the cone, and fine scars in the stroma. Additionally, by ophthalmoscope; there is a drop of oil red reflex, a scissoring sign by retinoscope, egg-shaped mires on keratometry with values between 45 and 52D in mild and moderate and more than 52D in advanced one, and a Munson sign. [2]; [4].

The early detection of subclinical cases among the risk population includes those with high astigmatism, a positive family history, twins of keratoconus patients, a history of repeated refraction adjustments with unsatisfied visual correction, and genetic defects such as Down syndrome. Early detection aims to stop the progression by less intensive intervention like cross-linking (with a 90% successful rate), then subsequent intervention can be done according to the need based on the patient's visual acuity, the presence of coma aberration, and other symptoms [5]; [6];[3].

Overall, the treatment of keratoconus from an early to advanced stage includes two approaches, first to stop progression and second to improve the vision: for the progressive early stage; the cross-linking effect to strengthen the cornea, prevent its protrusion and delay the need for keratoplasty with successful rate of 90%, also can improve correction of the vision by non-inversive option as glasses and contact lens [7]; [6].

For improving vision, either glasses or soft contact lenses are the choice in early cases; rigid permeable contact is less common; and others, especially keratoconus stable or cross-linking, are done for more irregular corneal surfaces and coma aberration; the scleral lenses are the choice.

If all previous options are not effective in improving vision, or thin corneal, superficial scarring; time surgical intervention is the option, which includes: intrastromal corneal ring segments used as refractive surgery alone or in combination with cross-linking with a successful rate of 97% with vision >20/40 and 74% with 20/20 [7];[8], the second option is corneal transplantation if the corneal is very thin, corneal scarring and in advanced cases, failed of other treatment options, which could be penetrated keratoplasty(PK) where whole corneal layers will be replaced by graft, or deep anterior lamellar keratoplasty(DALK) where the endothelium, Descemet membrane and deep stromal layer left and graft will be put on them, keratoplasty successful rate is 90% at the first time that decreases to 74% at the fifth year and further to 60% at tenth year [9]; [10].

Keratoconus represents 5% of the population in the Middle East region [4], more aggressive during puberty to 30 years old, the most active period of life that may interfere with a person's output and his or her quality of life, the early detection of the disease, and subsequently, surgical intervention that can improve or at least stop the progression of the disease, so improve the quality of that person's life.

Since there is not enough research addressing the knowledge and prevalence of keratoconus in Libya, and most of the keratoconus awareness tests the awareness of the general population and doesn't concentrate on keratoconus patients and their relative, from this endpoint; we conduct this research to form a solid knowledge about awareness of keratoconus Libyan patients and their cooperation to involve their relative and their keratoconus acquaintances in this research.

## **II. AIM:**

We aimed to test the general awareness of keratoconus patients and their relatives who have a refractive error, especially with astigmatism, about keratoconus nature and treatment, how it affects patients' lives, and also try to determine some risk factors, type of surgery if present, and how it changes the patient's life.

## **III. METHODOLOGY:**

### **3.1. Study data:**

A descriptive cross-sectional questionnaire, that involves keratoconus Libyan patients and their relatives who have refractive errors such as myopia and astigmatism and are aging above twelve years old. The sample size was calculated by EPI Info 7.2.6.0 version, where the sample size at the 95% confidence level is 73; our sample is 83. It was collected as a hospital-based conventional sample, a snowball sample, by asking patients to call for another keratoconus patient. The questionnaire was collected from previous literature reviews and tested by Cronbach's Alpha equal to 8 via SPSS 23 version for 30 participants; they weren't involved in this article, the questionnaire was both; an interviewing questionnaire for those collected as a conventional sample or online questionnaire for those who collected as snowball sample in addition to putting the online questionnaire in social

media application like Facebook (in both medical and popular groups), WhatsApp in popular and medical groups asking groups' participant to popular our questionnaire through the period between 25<sup>th</sup> November/2023 to 25<sup>th</sup> January/2024.

### **3.2. Sample collection and study procedure:**

The sample collected as either hospital based conventional sample and snowball sample, the collection of the data done as interviews questionnaire, for those how collected from the hospital, we involve all keratoconus patients whose came to corneal outpatients department in Benghazi teaching eye hospital, where in this department there are 25 to 30 patients per day, two days per week, at least half of those patients are keratoconus, advanced type at period of data collection there was visitor corneal specialized doctors came to do keratoplasty, we came one day per week, interviewed the patients and fill questionnaire, ask him to send an online questionnaire link, for their relative who has refractive error or keratoconus, moreover; we put the questionnaire social media as Facebook in both medical and popular groups, asking people whose keratoconus or relative to keratoconus and has refractive error to fill the questionnaire and send the link to another people with same situation.

The time of sample collection was done during the period between the 25<sup>th</sup> of November/2023 and to 25<sup>th</sup> of January/2024.

The questionnaire was divided into two parts. The first one has six questions to determine the sociodemographic state of the patient, where the residency and current address translated to urban and rural areas. The second part consists of ten questions that determine the medical state of the patient and present some risk factors such as allergy, positive family history, pregnancy, and their effect on the eye. The third part tests the knowledge of the patients about keratoconus by asking six simple questions. The fourth part determines the disease and surgical intervention effect on patients' lives in general, with six questions and one question to mention the data of surgical interventions. The last part asks patients if they have relatives with keratoconus and whether they do investigations, and asks them to help us publish the online questionnaire.

### **3.3. Data analysis:**

We used the IBM SPSS 23 version for the analysis of our data, to calculate the patients' awareness; which is determined by the third part of the questionnaire, where we exclude the second question in this part as it determines the source of the knowledge, we give first, third, fourth and sixth one point for true answer, for third question that ask about nature of keratoconus, we consider both thinning and inflammation of the cornea as a true answer, sixth question that ask about eye rubbing effect; it is true if patient answer either; it causes keratoconus or harm the eye, for fifth question that ask about treatment options; for one true answer we gave one point (surgery, glasses, contact lens last two as optical correction in early stage), if choice more than one true option we gave two points, with total score of six, then calculate the percentage, anyone above 60% consider as aware.

Also, by using cross-tabulation, we calculated the correlation between the keratoconus and either; residency, current address, presence of the allergy with their specific type, family history, or pregnancy for married women.

Besides, we determine the level of the keratoconus effect on the patient's life by answering the first two questions from the fourth part of the questionnaire. The first question takes one point, the second one points if it just affected one aspect of the life, and two points for a change of study or work that affects more than one aspect of the life with a total score of 3. The result is zero if there is no effect on the life, one for a mildly affected life, two for a moderately affected life, and three for a severely affected life. The surgical effect was tested by two questions (5<sup>th</sup> and 6<sup>th</sup> questions of the Part 4 questionnaire), with a result of zero for not satisfying patients' expectations, one for satisfied, and two for very satisfied.

### **3.4. Benghazi Teaching Eye Hospital data:**

It is the only eye hospital in Benghazi city, and as mentioned in its name, it is considered one of the biggest teaching centers in east Libya, the data collected from the corneal outpatient department shows that it receives 200 patients per months, where there are around 50 patients per day, two days a week.

### **3.5. Ethical consideration:**

The responsible body to give ethical approval for this study is the Libyan National Committee for Biosafety and Bioethics, adhering to national regulations. Additionally, endorsements were obtained from key local stakeholders: the Benghazi Teaching Eye Hospital, and the Ophthalmology Department.

## IV. RESULT:

83 Libyan participants were involved in this study; 58 of them were collected as a conventional sample, and the remaining 25 were from an online survey. Their sociodemographic data is illustrated in Table 1, with their results of level of education according to the third part of the questionnaire:

Table 1: illustrates the sociodemographic state of our sample:

Variants:	The number of participants:	Percentage:	Aware:	Unaware:	p-value: via chi-square:
Age group:					0.87% (Pearson chi-square = 0.025).
12 to 30 years old:	38	45.8%	29	9	No correlation.
More than 30 years old:	45	54.2%	35	10	
Gender:					0.11% (Pearson chi-square = 2.45).
Male:	52	62.7%	21	10	No correlation.
Female:	31	37.3%	43	9	
Residence:					0.72% (Pearson chi-square = 6.14).
Urban:	56	67.5%	48	15	No correlation
Rural:	27	32.5%	16	4	
Previous residence:					0.62% (Pearson chi-square = 8.96).
Urban:	56	67.5%	47	14	No correlation.
Rural:	27	32.5%	17	5	
Academic level:					0.062% (Pearson chi-square = 5.49)
Non:	2	2.4%	2	0	No correlation.
elementary to secondary:	26	31.3%	16	10	
collage or higher:	55	66.3%	46	9	
Work:					0.28% (Pearson Chi-square = 10.89)
Medical stuff:	7	8.4%	6	1	No correlation.
Housewife:	14	16.8%	11	3	
Free business:	9	10.8%	7	2	
Teacher:	14	16.8%	13	1	
Officer:	14	16.8%	11	3	
Student:	17	20.5%	12	5	
Others:	8	9.9%	4	4	

The second part of the questionnaire reviews some risk factors thought to be associated with keratoconus, such as allergy and its type, rubbing of the eye, positive family history, pregnancy, and state of the eye during pregnancy, it also illustrates the state of vision problem, the result of the second part of the questionnaire illustrated in Table 2.

Table 2: shows some risk factors associated with keratoconus occurrence in our participants:

Variant:	The number of participants :	Percentage:	Keratoconus :	Others:	p-value by chi-square:
Do you have an allergy?					
Yes:	64	77.1%	57	7	(Pearson chi-square=12.67)
No:	19	22.9%	12	7	
					Strong correlation.
If you have an allergy, which type of allergy do you have?					
Allergic conjunctivitis:	20	24.1%	20	0	(Pearson Chi-square=30.8)
Allergic rhinitis:	7	8.4%	6	1	
Asthma:	5	6%	3	2	No correlation.
Eczema:	5	6%	5	0	
More than one:	27	32.5%	23	4	
Non:	19	22.9%	12	7	
How frequently do you rub your eyes per day?					
Never:	6	7.2%	4	2	(Pearson Chi-square=17.56)
Rarely:	11	13.3%	7	4	
Sometime:	33	39.8%	28	5	No correlation.
Frequently:	26	31.3%	24	2	
Always:	7	8.4%	6	1	
Which type of vision problem do you have?					
Refractive error and wear glass:	8	9.6%	It is the primary criterion for comparison.	It is the primary criterion for comparison .	It is the primary criterion for comparison.
Refractive error and wear contact lens:	2	2.4%			
LASIK or refractive surgery:	2	2.4%			
Keratoconus:	69	83.1%			
Others:	2	2.4%			
Do you have a relative with keratoconus?					
Yes:	28	33.7%	23	5	(Pearson Chi-square=3.66). No correlation.
No:	53	63.9%	44	9	
I don't know:	2	2.4%	2	0	

If you have a positive family history of keratoconus, the degree of the relatively is:					0.22% (Pearson Chi-square=15.25).
Non:	55	66.3%	46	9	No correlation.
First:	18	21.7%	16	2	
Second:	6	7.2%	3	3	
Third:	4	4.8%	4	0	
For the female gender, are you married?					0.86% (Pearson Chi-square=9.99)
Yes:	23	27.7%	18	5	No correlation.
No:	29	35%	27	2	
I am male:	31	37.3%	24	7	
If you are a married female. Do you have children?					0.86% (Pearson Chi-square=10).
Yes:	3	3.6%	4	0	No correlation.
No:	29	35%	26	2	
I am a single female:	31	37.3%	24	7	
I am male:					
If you are a married female and have children, did you note any vision change during pregnancy?					0.81% (Pearson Chi-square=14.3)
No change:	8	9.6%	6	2	No correlation.
Vision gets worse:	9	10.9%	6	3	
Vision gets better:	0	0%	0	0	
The first keratoconus diagnosis was during pregnancy:	3	3.6%	3	0	
I have no children:	3	3.6%	4	0	
I am a single female:	29	35%	26	2	
I am male:	31	37.3%	24	7	

Regarding the third part of the questionnaire, which crucially detects the level of patients' awareness, the answers of the patients and the level of awareness are illustrated in Table 3:

Table 3: illustrate the result of the third part questionnaire; regarding participants' awareness:

Variant:	number of participants:	Percentage:	Aware:	Unaware:
Do you have information about keratoconus:	65	78.3%	36	2
Yes:	18	21.7%	1	17
No:				
What is the source of your knowledge about keratoconus?				
Doctor:	11	13.3%	11	0
Educational lecture:	1	1.2%	1	0
Media:	2	2.4%	0	2
Relative with keratoconus:	4	4.8%	4	0
I am keratoconus:	59	71.1%	48	11
Non:	6	7.2%	0	6
What happens in keratoconus?				
Thinning of the cornea:	44	53%	44	0
Thickening of the cornea:	4	4.8%	3	1
Inflammation of the cornea:	8	9.6%	7	1
I don't know:	27	32.5%	10	17
Does keratoconus result in vision impairment?	76	91.6%	64	12
Yes:	0	0%	0	7
No:	7	8.4%	0	0
I don't know:				
What is the treatment of keratoconus?				
Glasses:	0	0%	0	0
Lens:	1	1.2%	0	1
Surgery:	55	66.3%	46	9
Eye drops:	0	0%	0	0
More than one:	16	19.3%	16	0
No treatment:	1	1.2%	1	0
I don't know:	10	12%	1	9
Regarding eye rubbing (friction), what are your thoughts?				
Save:				

Cause eye allergy and itching:	0	0%	0	0
Harmful to the eye:	3	3.6	0	3
Cause keratoconus:	39	47%	29	10
I don't know:	34	41%	33	1
	7	8.4%	2	5

Regarding the fourth section of the questionnaire, which typically assessed how keratoconus affected patients' lives in two straightforward questions, it asked those who had surgery for their opinions on the procedure and how it had affected their lives, the result is illustrated in Table 4:

Table 4: illustrate keratoconus and surgical effect on patient's life:

Variant:	Number of the participants:	Percentage:
Effect of the life:		
1. Did the keratoconus interrupt your life:	59	71%
• Yes:	11	13.3%
• No:	13	15.7%
• I'm not keratoconus		
2. If your life is affected by keratoconus, the sort of affection is:		
• Study:	18	21.7%
• Work:	12	14.5%
• Driving:	4	4.8%
• I have to change my study brunch:	6	7.2%
• I have to change my work nature:	1	1.2%
• More than one option:	18	21.7%
• Non:	11	13.2%
• I'm not keratoconus:	13	15.7%
Result of those questions: Keratoconus effect on patients' life according to keratoconus patients (69 patients):		
Not affected:	21	31%
Mildly affected:	0	0%
Moderately affected:	25	36%
Severely affected:	23	33%
For the type of surgery intervention if		



present, and the patient's opinion about it:		
1. Have you undergone any surgical procedures for keratoconus? If so, please select the most recent intervention:		
Cross linking:		
Intrastromal corneal rings:	16	19.3%
Keratoplasty:	1	1.2%
Refractive surgery:	39	47%
Others:	0	0%
No surgery for me:	0	0%
I'm not keratoconus:	14	16.8%
2. How did your vision change after surgery:	13	15.7%
Gets better:		
Gets worse:	37	44.6%
No change:	0	0%
I require additional surgery:	18	21.7%
No surgery for me:	1	1.2%
I'm not keratoconus:	14	16.8%
3. How has your life changed since the surgery?	13	15.7%
Gets better:		
Gets worse:	36	43.3%
No change:	2	2.4%
No surgery for me:	18	21.7%
I'm not keratoconus:	14	16.8%
Result of patient's opinion about the effect of the surgery on their life and vision:	13	15.7%
Not satisfied:		
Satisfied:		
Very satisfied:	18	21.7%
No surgery for me:	2	2.4%
I'm not keratoconus:	36	43.3%
	14	16.8%
	13	15.7%

In the last part of the questionnaire, there is concern about reinforcing the positive family history and if their relative did any investigation to exclude keratoconus, and ask for patients' help to send the online questionnaire to their relative who has refractive problem or keratoconus, result mentioned in Table 5.

Table 5: illustrate the result of the last part questionnaire:

Variant:	The number of participants:	Percentage:
Do you have a positive family of keratoconus:		
Yes:	27	32.5%
No:	55	66.3%
I don't know:	1	1.2%
Has your relative conducted any tests to rule out keratoconus?		
Yes:	27	32.5%
No:	5	6%
I don't know:	51	61.4%
Could you assist us in publishing this questionnaire via an online link for your family members who have keratoconus or refractive errors?		
Yes:		100%
No:	83	0%
	0	

Nevertheless, all patients consented to assist in disseminating the questionnaire to their relatives. Among the patients with a positive family history, 27% were requested to send the questionnaire to any relatives with refractive error. However, only 25 participants were obtained through the online questionnaire, which was also promoted through social media. This indicates a relatively low level of cooperation from either the patients themselves or their relatives, despite their initial agreement.

Also, if we compare the correlation between the type of surgical intervention and the patient's satisfaction, the result is shown in Table 6, with a p-value of 0.00% that indicates a strong correlation between patients' satisfaction and the type of surgical intervention (Pearson chi-square=119.78).

Table 6: illustrate the patients' satisfaction according to type of surgical intervention:

Type of surgery:	Not satisfied:	Satisfied:	Very satisfied:
Cross-linking:	11	2	3
Intrastromal corneal rings:	1	0	0
Keratoplasty:	6	0	33

## **V. DISCUSSION:**

Keratoconus, a progressive corneal ectasia affecting primarily adolescents and young adults (approximately 1/1000 to 1/375 of the population, with a higher prevalence of 5% in the Middle East according to a recent meta-analysis), exhibits a concerning tendency to progress within this crucial reproductive age group, particularly in individuals under 30 years old. This necessitates early detection and intervention, as untreated keratoconus can lead to irreversible vision loss, rendering it the second most common cause of keratoplasty [11]; [12]. Therefore, robust screening programs targeting high-risk groups are essential to halt disease progression and preserve visual function.

To determine the target population for screening, we need to know the disease risk factor that include: age as puberty and change hormonal state could associated with disease progression, however; in our research there was no correlation between type of the surgery that done to the patients and age groups( $p$ -value =0.6) where keratoplasty performed to 18 patients under 30 years and 12 participants above 30 years, moreover; no correlation between gender and keratoconus( $p$ -value 0.22%, however keratoconus female population attend clinic more, female to male 5:3) that agree with “risk factor foe developed keratoconus: a much pair case-control study” that published in 2021 [13], on the other hand; it disagree with “keratoconus clinical finding according to different age and gender groups” that published in 2008 [14], regarding the residency there was strong correlation between urban and rural area ( $p$ -value=0.028%, where 61% {versus 39%} of keratoconus patients came from urban),that the same result with “incidence of keratoconus and its Association with comorbid condition, A Nationwide Cohort Study from South Korea” that published in 2020 [15], and disagree with “A hospital-based study on clinical data, demographic data and visual function of keratoconus patients in central China” that demonstrate more keratoconus incidence in rural area [16].

Additionally; there was a strong correlation between allergy and keratoconus (0.01%), however, no correlation between keratoconus and type of allergy ( $p$ -value 0.057%), also; no correlation was detected between keratoconus and eye rubbing ( $p$ -value=0.35%) that disagree with “the correlation between eye rubbing and keratoconus: a Review” that published in 2019, that reviews many studies regard correlation between eye rubbing and keratoconus [17]. Unfortunately; no correlation between positive family history and keratoconus ( $p$ -value=0.88%) might be at odds with numerous studies, such as “A hospital-based study on clinical data, demographic data and visual function of keratoconus patients in central China” and “Association between family history and keratoconus” study and several additional studies [16]; [18]. Additionally, no correlation was found between pregnancy and keratoconus according to our result ( $p$ -value 0.81%) which disagrees with "the pregnancy-induced progressive keratoconus study” published in 2011, the study demonstrated the occurrence of keratoconus progression in pregnant females who had no prior history of progression or associated factors before pregnancy [19].

Regarding awareness, there was good awareness about keratoconus nature and treatment option among keratoconus patients (64% was aware), most of them know well about nature of disease (44% answered thinning of cornea, and 7% inflammatory nature), as cause of progressive diminution of vision (64%), treatment options (46% answered surgery as an option and 16% answered more than one true options) and eye rubbing behavior (33% as a cause of keratoconus, 29% harmful to the eye and 2% of aware patients, they didn't know) with  $p$ -value 0.00%, as most of the study concern about keratoconus awareness in general population, our study regard the keratoconus and their relative awareness about keratoconus and their attitude about the genetic, progress nature and treatment options, during analysis our data; we found that; there was no correlation between level of the awareness and each of the following: age, gender, academic level, work nature nor residency that not correlated to “The level of Awareness of Keratoconus Among the General Population in Hail region, Saudi Arabia” that detect association between awareness of general population and their age, academic level and family history [20].

Regarding the keratoconus life affection by the nature of the disease; 31% of them do not affect their life (as it was unilaterally, 11% of unaffected patients underwent keratoplasty), 36% were moderately affected and 33% severely affected their life. Moreover; their satisfaction with surgical intervention (where 59 of keratoconus patients in our sample had a surgical intervention) was 66% of them had keratoplasty with 85% very satisfied and only 15% unsatisfied, regarding cross-linking (16 keratoconus) 69% unsatisfied,13% satisfied, 18% very satisfied (The reason may be attributed to the fact that the majority of patients anticipate an improvement in their vision rather than the prevention of further deterioration), about intrastromal corneal rings only one patient, who was unsatisfied, however; this result has a big limitation because of unrelated numbers between different surgical option.

That's an interesting point about the low response rate in our study, even though all participants initially agreed to have the questionnaire shared with their relatives with refractive errors or keratoconus. The 24% of our population via online questionnaire, and as online questionnaire was also published by other social media in both medical and public groups, suggests several potential reasons for the poor cooperation, that could be due to either uncooperative keratoconus patients or their relatives, lack of knowledge of benefit of this questionnaire (however; I explain the benefit on questionnaire and presented myself at first of questionnaire and ask them kindly to fill questionnaire and ask them to published survey at end of this survey, moreover, name of the patients and contact address was optional, to protect patients' privacy), time and frequently of questionnaire sharing (we published it since 25th November 2023 up to 25th January 2024, with republishing and activated it every two weeks, we published it in ophthalmic groups asking ophthalmology doctor to share it, and general medical groups and public groups on Facebook and WhatsApp groups), too long questionnaire (however; we designed the questionnaire to be not long, easy understand, slang, with determined risk factor (in short nine questions) , knowledge (in short six questions), keratoconus effect on the life (in two questions) and type of the surgical intervention and patients feedback (in simple three questions) then re-asking about positive family history and asking them to sharing survey with relatives or same patients.

A need to increase awareness among patients about the importance of family history, and the need to investigate any keratoconus patients, with high astigmatism, frequent change of glasses, also; the benefit of early detection to stop progression and avoid invasive surgical intervention, also to clarify the treatment option, and its purposing and divided them into two categories: one to prevent progression, and other to correct the vision, to clarify the possibility to need more than one intervention to reach target correction.

Our questionnaire, designed to briefly assess multiple aspects of keratoconus, provided a preliminary overview. However, its limitations highlight the need for more focused research. This includes screening programs for relatives with refractive errors, with motivational incentives to accurately assess family history's role. Additionally, clinical research independent of patient reports, alongside ongoing awareness programs, can refine our understanding and increase participation.

## **VI. CONCLUSION:**

Overall awareness of keratoconus (78%) and their relative who contributed to the questionnaire (71% were aware) is good, however; there was a weak response from keratoconus relatives in contribution to this questionnaire, which raised the need to upgrade awareness about positive family history and encourage the screening programs for high-risk groups (keratoconus relative with refractive error), moreover; we need more programs to clarified the option and purposes of surgical intervention and benefit of early detection and treatments.

Further clinical research to detect subclinical keratoconus is needed, in addition to research about different surgical options with clear awareness about the benefit of each intervention along the way with patients' feedback upon them.

## **VII. LIMITATION:**

**Sampling bias:** Our study's reliance on participants recruited from a corneal clinic for keratoplasty potentially introduced a selection bias. This limited exposure to individuals with earlier, subclinical stages of keratoconus, who might exhibit different levels of awareness than those seeking advanced treatment. This limits the generalizability of our findings to a broader population with diverse disease severity. **Restricted online reach:** The online questionnaire aimed to assess regional awareness beyond the clinic sample yielded insufficient data. With only 20 responses, all from Benghazi (the same city as the clinic), the results lack geographical representativeness and cannot be extrapolated to the entire Libyan region. This highlights the need for future research employing diverse recruitment strategies (e.g., a multi-center approach) to capture a more complete picture of awareness levels across the country. **Reliance on self-reported data:** The dependence on patient-reported information through questionnaires introduces potential limitations related to recall bias and subjective interpretation. Future research incorporating objective clinical data (e.g., corneal topography, and diagnostic tests) could provide a more reliable and comprehensive assessment of keratoconus awareness and diagnosis.

## VIII. DECLARATION

The work presented in this paper, titled “Keratoconus Awareness and Disease Effect on Life of Keratoconus Libyan Patients” has not been submitted to any other journal for publication. All data collected for this research was kept confidential and informed consent was obtained in writing from all participants. I used the language model Bard from Google AI to review my language and enhance the academic tone of the manuscript.

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