

Differences in minimal disease knowledge of keratoconus patients: results from an international survey

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ABSTRACT

Background/aims The objective of this multicentre, multinational, prospective study was to assess the level of basic understanding that individuals with keratoconus possessed about their condition.

Methods We recruited 200 active keratoconus patients who were under regular review, and cornea specialists established a standard of ‘minimal keratoconus knowledge’ (MKK) that included an understanding of the definition, risk factors, symptoms and treatment options for the condition. We collected data from each participant regarding their clinical characteristics, highest level of education, (para)medical background and experiences with keratoconus within their social circle, and calculated the percentage of MKK attained by each patient.

Results Our findings revealed that none of the participants met the MKK standard, with the average MKK score being 34.6% and ranging from 0.0% to 94.4%. Furthermore, our study showed that patients with a university degree, previous surgical intervention for keratoconus or affected parents had a higher MKK. However, age, gender, disease severity, paramedical knowledge, disease duration and best-corrected visual acuity did not significantly affect the MKK score.

Conclusions Our study demonstrates a concerning lack of basic disease knowledge among keratoconus patients in three different countries. The level of knowledge exhibited by our sample was only one-third of what cornea specialists would typically anticipate from patients. This highlights the need for greater education and awareness campaigns surrounding keratoconus. Further research is needed to determine the most efficient approaches for enhancing MKK and subsequently improving the management and treatment of keratoconus.

INTRODUCTION

Successful management of keratoconus necessitates patients and ophthalmologists to achieve shared decision-making. This approach ensures that treatment options align with the patient’s personal values and preferences, as well as their level of knowledge regarding the disease.¹ Unfortunately, many patients lack even minimal knowledge about keratoconus, leading to worry, fear

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Shared decision-making can be beneficial for patients who are confronted with challenging decisions related to their treatment. However, when patients lack essential knowledge about their condition, it may increase their levels of worry and anxiety and cause unrealistic expectations about their disease’s progression. In a recent study conducted in Switzerland, it was discovered that there was a significant disparity between the expectations of caregivers and the knowledge of patients suffering from keratoconus. While these results may be unique to Switzerland, it is uncertain whether they can be applied to other countries. Therefore, the aim of the current study was to evaluate the level of basic knowledge about keratoconus among patients on an international scale.

WHAT THIS STUDY ADDS

⇒ The findings of this multicentre, prospective survey suggest that extra efforts are required to educate keratoconus patients regarding their disease. The educational matters should target at enabling patients to participate in a joint decision-making process. Considering that patients with different backgrounds might require different information, selection of educational material should be tailored to the patient’s needs.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Especially the positive parental influence on children’s health knowledge contributes to the high demand for more research in this field. The poor level of knowledge in keratoconus calls for further studies assessing knowledge of patients with chronic eye disease. This will allow to improve educational efforts and to develop new approaches to assure that patients suffering from a chronic eye disease can meet their caregivers with an adequate level of disease knowledge to facilitate shared decision-making.



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and unrealistic expectations about the disease and its treatment options.^{2,3} Despite the importance of patient knowledge, there is currently limited information available about the level of understanding among patients with chronic eye conditions.⁴

In a previous study, cornea specialists established a standard of 'minimal keratoconus knowledge' (MKK) that included understanding the definition, risk factors, symptoms and available treatment options for keratoconus. A significant lack of knowledge among keratoconus patients in Switzerland was found.⁵ However, it is possible that the knowledge level in other healthcare systems is greater, given the existence of patient-oriented websites (eg, www.defeatkeratoconus.com), social media patient groups and national programmes in other countries (eg, Fight for Sight in the UK).⁵ In the Swiss healthcare system, general ophthalmologists typically treat keratoconus patients and only refer them to cornea specialists for advice on treatment options.⁶ However, a survey of general ophthalmologists revealed a significant discrepancy between their knowledge of keratoconus and the expectations of cornea specialists.⁶ Poor recall of symptoms and risk factors may explain why ophthalmologists diagnose relatively few cases of keratoconus, leading to delayed intervention and inefficient care.⁶ It is important to note that these results may not apply to other countries due to unique factors in the Swiss healthcare system.⁵ Therefore, this study aims to evaluate the MKK of patients on an international scale.

MATERIALS AND METHODS

Study design

This study was a multicentre, prospective, face-to-face survey enrolling keratoconus patients consecutively at four cornea/ocular surface disease clinics in UK (n=2), USA (n=1) and Ireland (n=1). We enrolled patients who had previously received the diagnosis of keratoconus from a board specified corneal specialist, being currently under active care of the cornea clinic and had sufficient English language skills. Our aim in using the latter selection criterion was to eliminate the likelihood that inadequate language proficiency would negatively impact response quality. Criteria for exclusion composed of the inability to comprehend the English questionnaire due to factors such as language difficulties, mental illnesses or dementia; patients who were under 18 years of age; patients under guardianship; those who had previously participated in this study; and the involvement of the researcher, their family members, associates or other dependents. We notified eligible keratoconus patients who attended regular consultations at the four participating study centres about the study's availability. Following verbal consent given at the end of their regular consultation, individuals were promptly interviewed in person. It was decided to use a survey approach due to the ease of use, reduction of risk for misunderstanding as well as a probably more accurate reply as compared with a self-completed questionnaire or online survey. No incentives for study participation were

offered. Each participant provided information on age, gender, highest level of education completed, any (para) medical background and personal experiences with keratoconus in their social context. The duration since the diagnosis of keratoconus and the present treatment for keratoconus were also evaluated. At least one interviewer per study centre received verbal and written instructions for conducting the interviews. All interviewers were native English speakers with a specialised professional background as either a study nurse or a certified ophthalmologist working in the ophthalmology department. Each question was read aloud and the corresponding answers were noted. Interviewers were given instructions not to inquire respondents how many answers they should provide per question.

Questionnaire development

In an earlier study⁵ assessing MKK in keratoconus patients, a questionnaire was created through a literature review and input from a focus group consisting of four cornea specialists and two optometrists specialising in contact lens-fitting. For this international study, the questions of the previous study were translated into English and discussed with all authors. There was an agreement that in contrast to the previous study,⁵ the questions of risk factors and triggers was not separated and therefore the original questionnaire was slightly reduced from six to five questions. The questions were composed at a recommended reading level appropriate for the eighth grade. Online supplemental table 1 specifies the minimum level of knowledge that we deemed necessary.

Apart from the knowledge questions, we gathered clinical data on time of keratoconus diagnosis, best-corrected visual acuity, corneal steepness (measured by Kmax), degree of ectasia (assessed by Belin Ambrosio Deviation Score) and the type of previous treatments. We finalised the form of questionnaire after testing with a group of five keratoconus patients.

Data analysis and statistics

Two cornea specialists independently scored and ranked the responses using a scoring sheet with predetermined correct answers. If a participant's statement during the interview suggested a correct answer but did not precisely match the predetermined answers, it was noted and reviewed by two assessors for discussion. Any disagreements were settled through a consensus reached by the same two assessors.

First, we counted the total number of correct answers and calculated the proportion of correct MMK (correct replies/MKK (online supplemental table 2)) for all questions. A total of 18 correct answers were possible. To determine a person's MKK, we multiplied the total number of correct responses by 100 and divided the result by 18.

Second, we used a linear multivariate regression model to analyse the impact of several independent variables, including age (measured on an interval scale), gender

(male or female), highest level of education attained (university or other), (para)medical background (yes or no), experience with keratoconus in a social context (yes or no) and duration of keratoconus, on the dependent variable, which was the cumulative proportion of correct responses. To account for possible confounding due to differences in disease duration between patients in the different centres, we added an indicator variable for disease duration as an additional independent variable to the multivariable analysis. In an additional analysis, we explored whether a higher MKK was associated with better best-corrected visual acuity, greater severity of keratoconus as indicated by higher Kmax values, or a history of surgical treatment. Finally, we assessed whether introducing an additional indicator variable coding for participating centre made an independent contribution to assess variability of MKK in the multivariable model.

We did not perform a formal sample size calculation since the purpose of this study was solely exploratory. We statistically tested for differences between groups using parametric or non-parametric methods, depending on expediency. The analysis was carried out using the Stata V.16.1 statistical software package (StataCorp).

RESULTS

Reporting of patient characteristics

The study was conducted between October 2020 and November 2021. We enrolled 200 keratoconus patients (mean age 30.2 years (SD 11.3), range 18–72; 66% male) in four different keratoconus-specialised institutions in the UK, USA and Ireland. The average time since keratoconus diagnosis was 4.9 years (SD 6.88; range 0–35). There were no participants who had to be excluded due to inadequate English-speaking skills. The demographic data of the participants are displayed in online supplemental table 2.

MKK: performance

None of the participants reached MKK defined as 100%. The average MKK score was 34.6% ranging from 0.0% to 94.4%. Average MKK was highest in Liverpool (44.6%), followed by Lucerne (41.0%), Dublin (37.4%), Newcastle (32.6%) and Baltimore (24.0%). Multivariable analysis showed that participants with parents being affected by keratoconus (+11.5% (95% CI 1.8% to 21.3%); $p=0.021$), a university degree (+7.4% (95% CI 2.5% to 12.3%); $p=0.003$) and previous surgical interventions (+5.3% (95% CI 0.5% to 10.0%); $p=0.031$) had a higher MKK. Bilateral involvement, age, gender, severity of keratoconus in terms of Kmax value, paramedical knowledge, disease duration or best-corrected visual acuity did not significantly raise MKK. Excluding disease duration as a potential confounder of the analysis did not have an impact on the results. Percentage of correct answers overall and per study centre is displayed in online supplemental table 1.

MKK: definitions, risk factors and triggers

Out of the participants, 80 (40.0%) could recall protrusion, and 67 (33.5%) could recall corneal irregularity as

diagnostic indicators for keratoconus diagnosis. However, only 45 subjects (22.5%) could recall corneal thinning, which is also an important indicator. Only 2 subjects (1.0%) were able to correctly report all three relevant parameters. For the three most common risk factors for developing keratoconus, 89 subjects (44.5%) correctly stated eye rubbing and 63 subjects (31.5%) ‘positive family history’, while allergies ($n=26$; 13.0%) were rarely reported. Only 1 participant (0.5%) indicated all three criteria correctly.

MKK: symptoms, consequences of untreated keratoconus

Blurred vision was reported as a symptom of keratoconus by most participants ($n=150$; 75.0%), while other important symptoms such as double/distorted vision ($n=58$; 29.0%) and light sensitivity ($n=33$; 16.5%) were reported with lower frequency. Only 16 subjects (8.0%) correctly indicated all 3 important symptoms. The most commonly mentioned consequence of not treated keratoconus was visual deterioration progression ($n=150$; 75.0%). Other consequences, such as the need for corneal transplantation ($n=57$; 28.5%), the inability to fit glasses ($n=11$; 5.5%) or even contact lenses ($n=11$; 5.5%), were reported less frequently. Furthermore, 10 (5.0%) respondents indicated that the progression of keratoconus would impede them from continuing in their current profession. None of the respondents answered all questions correctly.

MKK: treatment options

The majority of participants ($n=133$; 66.5%) reported corneal cross-linking as a treatment method for keratoconus, followed by rigid contact lenses ($n=102$; 51.0%) and corneal transplant ($n=98$; 49.0%). Glasses, as the fourth option, were less often stated ($n=40$; 20.0%). Not one subject answered all questions correctly.

DISCUSSION

Main findings

In this multicentre, prospective survey involving patients from the UK, USA and Ireland, we confirmed the lack of disease knowledge by keratoconus patients in an international setting when compared with a previous study in Switzerland.⁵ None of the participants reached 100% MKK. Participants with keratoconus whose parents were also affected by keratoconus, who had a university degree or who had undergone a previous surgical intervention for keratoconus had a higher MKK score.

Results in light of existing literature

Currently, limited knowledge exists on the health literacy of the general public and individuals with chronic eye diseases. However, there is one article we found that investigated the health literacy level of patients with chronic retinal diseases and found it to be insufficient or challenging.⁷ Low health literacy has been demonstrated to be linked to a higher risk of complications such as diabetic retinopathy in individuals with type 2



diabetes.^{5 8} Furthermore, inadequate health literacy has been linked to decreased adherence to treatment among individuals with glaucoma.⁹ Muir and Lee proposed that delivering patient education tailored to individuals with low health literacy could be a way for eye care providers to enhance clinical outcomes and decrease disparities in healthcare.¹⁰

In a recently reported multicentre study⁵ in Switzerland, a low level of keratoconus patients' knowledge was reported. The current study allows a broad generalisation of those initial findings to other countries as it eliminates some Swiss particularities. In contrast to the previous study, the current study showed a significant higher MKK in patients with a university degree, patients with parents being also affected by keratoconus or patients with previous surgical interventions for keratoconus. The concept that education contributes to better health by providing improved employment and income opportunities and enabling individuals to reside in neighbourhoods that promote healthy lifestyles is supported by the positive effect of education level.¹¹ But there is paucity of literature regarding parental influence on chronic eye disease knowledge. With regard to health literacy there are studies such as Levin-Zamir *et al*¹² who reported a high association of health literacy with socioeconomic status and mothers' level of education. The question that arises in this context is whether an individual's health literacy can have an impact on the knowledge or health behaviours of others.¹³ The majority of literature data focuses on the influence of parental health literacy on the health behaviours and outcomes of their children.¹³ According to a systematic review, parents with low literacy skills were found to have less health knowledge and participate in behaviours that were less advantageous for their children's health in comparison to parents with higher literacy skills.¹⁴ Still, as stated by Schulz,¹³ there is high demand for more research on parental influence on children's health knowledge, to which this study contributes. When it comes to the effect of previous surgical experience on patients' knowledge, nothing is described in the ophthalmic literature to our knowledge.

Strengths and limitations

As far as we know, this is the first international multicentre study that investigates the minimal knowledge regarding common symptoms, risk factors, and available treatments among patients with keratoconus. One of the limitations of this study is that we used a convenience sample with a limited size.⁵ We recruited only patients who voluntarily agreed to take part in the study, which may have resulted in selection bias. It is possible that our sample consisted of individuals with higher-than-average levels of knowledge, leading to an overestimation of their understanding of keratoconus.⁵ We found differences in average MKK across the various participating centres. We were unable to explore these differences in more detail. We cannot rule out that differences in the socioeconomic demographics not captured in sufficient detail,

could have explained these differences. However, since our main focus was the assessment of MKK presence in these five cohorts, and that none of the centres had one single participant showing minimum knowledge, we believe that our overall conclusions are still valid and call for concerted efforts to increase disease knowledge of patients with keratoconus. Another limitation was the utilisation of a non-validated questionnaire.⁶ In the absence of such a standardised and validated questionnaire, we created a questionnaire in accordance with the recommendations published.¹⁵ The questionnaire solely satisfied the aspect of face validity, which is an significant but not deemed as a recommended component of questionnaire development.⁵ Nevertheless, the questionnaire proved adequate in demonstrating the notable difference between anticipated and factual knowledge of patients.⁵ The questionnaire was developed without consulting a patient group, this may have led to an overly difficult definition of MKK. After all, we employed a recall test, which is typically more challenging than a recognition test, like a multiple-choice test.⁵ Our methodology was justified as shared decision-making necessitates knowledge of the disease.¹⁶

Implication for research and practice

We affirm earlier reports, which showed that health is not coupled with knowledge.¹⁷ They evaluated the 'minimum medical knowledge' (MMK) that individuals should understand about usual signs and/or risk factors associated with four pertinent clinical conditions: heart attack, stroke, chronic obstructive pulmonary disease and HIV/AIDS.¹⁷ The minimum medical knowledge was also found to be as low as 32% and multivariable analysis revealed that individuals with a university degree, a (para)medical background, or prior experience with the disease had only slightly higher MMK levels compared with those without a university degree. Conversely, age and gender had no impact on the level of MMK.¹⁷ However, diverging from earlier findings, we demonstrate that this occurrence is also widespread among patients with chronic disease.⁵

There is an unmet need for better keratoconus awareness and educating patients. This is where digital technology can play a role, as we envisage that patient-focused websites, patient groups or internet forums moderated by experts can augment knowledge. This is especially pertinent since the majority of keratoconus patients are young and accustomed to digital platforms.⁵ However, although there are already patient-oriented websites (eg, www.defeatkeratoconus.com) and national programmes such as Fight for Sight in the UK or National Keratoconus Foundation (eg, www.nkcf.org) in the USA, MKK in these countries was not higher compared with other participating countries in this study. Furthermore, as previously stated,¹⁸ there is a pressing need for significant improvement in interdisciplinary patient care and information delivery by healthcare professionals such as contact lens specialists, ophthalmologists and corneal

specialists, in order to alleviate the effect of keratoconus on patients' quality of life.⁵

CONCLUSIONS

Modern treatment of keratoconus should involve patients in shared decision-making to empower them to make difficult treatment decisions and to improve the match between planned treatment options and patients' personal values.⁵ Therefore, it holds great significance to ascertain the patient's existing level of knowledge, which the treating physician anticipates from them.⁵ Our findings indicate that in different countries and healthcare settings, there is a notable difference between the expectations of caregivers regarding patients' knowledge of keratoconus and the actual knowledge of patients themselves. Interestingly, patients with a university degree, previous surgical intervention for keratoconus or if their parents were also affected by keratoconus showed a higher MKK. This discrepancy can result in inefficient care and misunderstandings.⁵ The low level of knowledge necessitates collective global education endeavours and new approaches to ensure that patients, especially those with chronic conditions, can meet their caregivers with an adequate level of knowledge about their disease.

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Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants but the study was conducted according to the standards of good clinical practice and the ethical principles for medical research involving human subjects as outlined in the Declaration of Helsinki. The local Ethics Committee 'Ethikkommission Nordwest- und Zentralschweiz, EKNZ' (ReqID-2019-00995) reviewed the protocol of this study and found that this study did not fall under the Swiss Human Research Act. Each study centre proceeded according to internal guidelines. In Liverpool and Newcastle, the study was approved by NHS Health Research Authority as an audit approval. The study was further approved by the University of Maryland, Baltimore's IRB and in Dublin ethical approval for this project was granted by the Royal Victoria Eye and Ear

Hospital Ethics Committee. All methods were carried out in accordance with relevant guidelines and regulations. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request. The datasets generated and/or analysed during the current study are not publicly available due institutional policy but are available from the corresponding author on reasonable request.

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