

Do Patients With Keratoconus Have Minimal Disease Knowledge?

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Purpose: To assess whether Swiss adult citizens diagnosed with keratoconus have the minimal knowledge that a corneal specialist would expect they should have.

Methods: Experts defined the “minimal keratoconus knowledge” (MKK) with respect to definition, risk factors, symptoms, and possible treatment options of keratoconus. A survey was performed in 167 patients with keratoconus [mean age 38.8 years (SD 13.9), 77.7% male] in 5 specialized institutions. Of each participant, salient clinical characteristics, highest educational level, paramedical background, and specific health experience with keratoconus in the social surrounding were obtained. We calculated the proportion of MKK and examined whether patients with higher education and greater disease experience would perform better than those from other groups in multivariate analyses.

Results: No single citizen reached 100% MKK. The mean MKK was 35.2%, and the range was 0% to 76.2%. Participants with a university degree had only a moderately higher MKK [+8.7% (95% confidence interval: 4.4–13.0); $P < 0.001$]. Per age decile, the MKK declined by 3.1% (95% confidence interval: 1.2–4.9), $P = 0.002$. Disease duration, severity of keratoconus in Kmax values, and history of surgical treatment did not significantly increase MKK. Surprisingly, MKK was also lower in patients with a paramedical background [−6.3% (−14.1 to 1.4); $P = 0.107$].

Conclusions: This sample of Swiss patients with keratoconus did not know more than a third of the MKK. We found a little difference within various subgroups. There is a substantial mismatch between caregivers’ expectations of patients’ knowledge and patients’ active knowledge regarding their condition. This may lead to an inefficient care delivery and misunderstandings.

Key Words: minimal knowledge, keratoconus, interview survey

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State-of-the-art management of keratoconus requires that patients and doctors engage in a shared decision-making process. Shared decision-making enhances outcomes among patients and leads to better congruence between pursued treatment options and patient’s personal value.¹ However, active participation requires the patient to have at least a minimal level of understanding of the disease condition.² Knowledge deficiency promotes patients’ concerns and fears and leads to unrealistic expectations about the course of the disease.³ It has been shown that there is a dramatic lack of knowledge in the general public about typical signs and risk factors for important clinical eye conditions (such as age-related macular degeneration).^{4,5} Up to now, little is known about the level of knowledge of patients affected by a chronic eye disease.⁶

Typically, clinicians looking after patients with chronic conditions have expectations toward their disease knowledge. However, to date, it is unknown whether patients with keratoconus meet this expectation. In this study, we define a “minimal medical knowledge” (MMK) regarding definition, risk factors, symptoms, and possible treatment options of keratoconus by a scale that can measure individual knowledge between 0% and 100%. We assume that patients with higher education and greater disease experience should reach the maximum MMK more often than those who do not. The reason for this hypothesis is the assumption that patients with some paramedical background or those confronted with a greater disease experience because of a more advanced form of keratoconus probably have acquired more knowledge than those without. By performing this survey on MKK in our patient cohort, we wanted to find out whether there is a need to improve patient education to achieve a shared decision-making in patients with keratoconus.

METHODS

Study Design

We conducted a multicenter face-to-face interview at 4 corneal clinics and 1 contact lens fitting center in the German-speaking part of Switzerland.

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Questionnaire Development

This questionnaire was developed on the basis of a literature review and discussions held by a focus group of 4 corneal specialists and 2 contact lens-fitting optometrists. They defined the minimal knowledge an average patient with keratoconus should have in relation to definition, risks and triggers, symptoms, and treatment options of the disease. They were instructed to state just the most common set of characteristics that should be known by every patient with keratoconus, excluding uncommon factors or unusual presentation of symptoms. Experts are supposed to know much more about the conditions (beyond 100%). Supplemental Digital Content 1 (see Appendix, <http://links.lww.com/ICO/B95>) defines what we considered minimal knowledge.

We transformed their statements into 6 questions and developed a questionnaire in German that could be completed within 5 minutes during the interview. For each question, we defined a minimal set of correct answers (see Appendix, Supplemental Digital Content 1, <http://links.lww.com/ICO/B95>). Besides the knowledge questions, we planned to extract the clinical information including the time point of keratoconus diagnosis, visual acuity, steepness of the cornea (Kmax), the extent of ectasia (using the Belin-Ambrosio Deviation score), and the type of previous treatments. We tested the questionnaire on 5 subjects to obtain the final form. We preprinted the questionnaires to optimize the course of the interview. The relevant ethics committees of Lucerne and Zurich reviewed the protocol of this study and found that this study did not fall under the Human Research Act.

Interviewers

Seven interviewers received an oral and written instruction on how to conduct the interviews. They trained the interview on 2 subjects each.

Participants

We informed eligible patients with keratoconus presenting for a regular consultation at the 5 participating study centers in the German-speaking part of Switzerland about the existence of the study. The inclusion criteria were a previous diagnosis of keratoconus and sufficient German language skills. With the latter selection criterion, we wanted to rule out that insufficient language skills would contribute to a poorer response quality. Exclusion criteria were the inability to follow the German questionnaire because of language problems; psychological disorders or dementia; patients aged younger than 18 years; patients under tutelage; previous enrollment into the current study; and enrollment of the investigator, his family members, employees, or other dependent persons. We enrolled patients willing to participate in the study in a prospective and consecutive manner. Face-to-face interviews were conducted immediately after the patients gave verbal consent at the end of the regular consultation. We obtained information on age, sex, highest educational degree, paramedical background, and specific health experience with keratoconus in the social surrounding from each participant. We also asked the duration since

diagnosis and their current treatment of keratoconus. We read each question and recorded the corresponding replies. We offered no incentives for study participation.

Statistical Analysis

First, we counted the cumulative number of correct replies, and for simplicity, we calculated the correct MMK proportion [correct replies/MMK (see Appendix, Supplemental Digital Content 1, <http://links.lww.com/ICO/B95>)] across all questions. Assessment of correct replies was performed in duplicate according to the predefined replies, and discordances between the assessors were discussed. In case of remaining disagreement, particularly if the participant used an unusual term, we classified the answer as correct. The total number of correct answer is 21. The MMK of a person is the total number of correct replies divided by 21. Second, we examined the influence of age (interval scaled), sex (female or male), highest educational degree (university or else), paramedical background (yes or no), and duration of keratoconus as independent variables, and the cumulative proportion of correct replies as the dependent variable using a linear multivariable regression model. Then, we examined whether visual acuity, severity of keratoconus in Kmax values, and a history of surgical treatment would have a higher MKK. For this purpose, we calculated the MMK for the corresponding variables.

We did not perform a formal sample size analysis because this study was purely exploratory. We performed the analysis using the Stata 16.1 statistical software package (StataCorp, College Station, TX).

RESULTS

Reporting of Patient Characteristics

During the study period from November 2019 to January 2020, we enrolled 167 patients with keratoconus [mean age 38.8 years (SD 13.9), 77.7% male] in 5 different keratoconus-specialized institutions. Time point since keratoconus diagnosis was on average 12.9 years (range 0–70). For detailed description of participants, see Table 1.

MKK—Performance

No single citizen reached 100% MKK. The mean MKK was as low as 35.2%, and the range was 0% to 76.2%. Multivariable analysis showed that participants with a university degree had only a moderately higher MKK {+8.7% [95% confidence interval (CI): 4.4–13.0]; $P < 0.001$ }. Per age decile, the MKK declined by 3.1% (95% CI: 1.2–4.9), $P = 0.002$. Disease duration, severity of keratoconus in Kmax value or Belin-Ambrosio Deviation Score, and history of surgical treatment did not significantly increase MKK. The higher the visual acuity, the lower the MKK [−6.3% (95% CI −16.5 to 4.00); $P = 0.229$]. Surprisingly, MKK was also lower in patients with a paramedical background [−6.3% (−14.1 to 1.4); $P = 0.107$].

TABLE 1. Characteristics of Study Population

Characteristics (n = 167)		%/SD
Male sex	129	77.7%
Mean age	38.8	SD 13.9
Education		
Mandatory school	7	4.2%
Secondary school	0	0.0%
University entrance diploma	1	0.6%
Apprenticeship	50	29.9%
Vocational school	27	16.2%
University	85	50.9%
Medical education, self-reported	17	10.2%
Keratoconus in social environment		
Parents	11	6.6%
Grandparents	3	1.8%
Siblings	17	10.2%
Children	7	4.2%
Uncle/aunt	6	3.6%
Cousin	3	1.8%
Partner	2	1.2%
Friends	5	3.0%
Affected eye		
Right	161	96.4%
Left	164	98.2%
Both	158	94.6%
Ways of improving visual acuity		
None	9	5.4%
Glasses	62	37.1%
Hard contact lenses	133	79.6%
Surgical interventions		
Corneal cross-linking	72	43.1%
Corneal transplant	18	10.8%
Intracorneal ring segments	1	0.6%
Other	2	1.2%
Best corrected visual acuity (Snellen Visus)		
Right	0.91	SD 0.26
Left	0.82	SD 0.30
Belin-Ambrosio Deviation Score		
Right	10.3	SD 11.4
Left	10.5	SD 11.5
Maximum keratometry (Kmax)		
Right	55.2	SD 8.98
Left	55.7	SD 11.88

MKK—Definitions, Risk Factors, and Triggers

Ninety-five participants (58.0%) recalled that corneal irregularity and protrusion are 2 diagnostic indicators for keratoconus diagnosis, whereas only 42 subjects (25.2%) named the third important indicator—corneal thinning. Only 12 subjects (7.2%) were able to state all 3 relevant parameters correctly. Of the 3 most important risk factors for the development of keratoconus, 89 subjects (53.3%) correctly stated “positive family history,” whereas allergies (n = 15; 9.0%) and younger age (n = 10; 6.0%) were uncommonly stated. Not 1 single participant stated all 3 criteria correctly. Regarding triggers, rubbing was stated most often (n = 65;

38.9%), and puberty (n = 23; 13.8%) and pregnancy (n = 6; 3.6%) were uncommonly stated. One participant stated all 3 triggers correctly.

MKK—Symptoms and Consequences of Untreated Keratoconus

Most participants stated that deterioration of vision was an important symptom of keratoconus (n = 152; 91.0%), whereas other important symptoms, including double vision (n = 44; 26.4%) and light sensitivity (n = 16; 9.6%), were less commonly stated. Six subjects (3.6%) stated all 3 important symptoms correctly. Regarding consequences of untreated keratoconus, progression of visual deterioration (n = 105; 62.9%) was most commonly stated. Other consequences, including the requirement of a corneal transplant (n = 47; 28.1%), the inability to fit spectacles (n = 25; 15.0%), or even contact lenses (n = 12; 7.2%), were less often stated. Six respondents acknowledge that keratoconus progression would impede from continuing working in the current profession. None of the interviewed persons answered all questions correctly. Interestingly, 36 subjects (21.6%) incorrectly stated that keratoconus progression would lead to blindness.

MKK—Treatment Options

Most participants stated that corneal cross-linking was one of the treatment modalities (n = 128; 76.7%), followed by rigid contact lenses (n = 124; 74.3%) and corneal transplant (n = 110; 65.9%). Spectacles, as the fourth option, was uncommonly stated (n = 36; 21.6%). Twenty-one subjects (12.6%) answered all questions correctly. Interestingly, subjects also named 2 less common treatment modalities: laser surgery (n = 14; 8.4%) and intracorneal ring segments (n = 3; 1.8%).

DISCUSSION

Main Findings

In this survey among Swiss patients with keratoconus, we found a dramatic lack of knowledge about the typical signs, risk factors, and treatment options. Overall, the patients did not know more than approximately one-third of the MKK. None of the participants reached 100% MKK. Contrary to our expectation, patients with a university degree or those confronted with a greater disease experience showed only little more specific knowledge. Even more surprisingly, patients with a paramedical background demonstrated lower MKK than those without such a background.

Results in the Light of Existing Literature

Up to now, little is known about the level of health knowledge in the public and patients with a chronic eye disease. Among the few exceptions, we found 1 article that evaluated health literacy levels in patients with chronic retinal disease and concluded an inadequate or problematic level of health literacy.⁷ In the case of type 2 diabetes, poor health

literacy level is associated with an increased risk of complications such as diabetic retinopathy.⁸ Furthermore, in patients with glaucoma, poor health literacy skills are associated with lower adherence to glaucoma treatment.⁹ Muir et al¹⁰ suggested that by providing patient education appropriate for patients with low health literacy, eye care providers have the opportunity to improve clinical outcomes and reduce healthcare disparities.

Strength and Limitation

To the best of our knowledge, this is the first survey investigating active knowledge on typical signs, risk factors, and treatment options in patients with keratoconus.

The following are the limitations of this study. We assessed a convenience sample of limited size. We enrolled only patients who were willing to participate in the study, which might have introduced selection bias, although we think that our respondents were more likely to score higher than average, leading to an overestimation of knowledge. We cannot rule out that some Swiss particularities impede broad generalizations of our findings to other countries. The level of keratoconus patients' knowledge in other healthcare systems might be higher because there are already patient-oriented Web sites (eg, www.defeatkeratoconus.com) and national programs (eg, Fight for Sight in the United Kingdom) in place. A further limitation was that we used a nonvalidated questionnaire. Because standard and validated questionnaires were not available, we designed one according to published recommendations.¹¹ The questionnaire fulfilled only the element of face validity, which is an important but not a sufficient element of questionnaire development. However, the questionnaire was sufficient to point at the substantial mismatch between expected and actual patient knowledge. Finally, this was a recall test, which is usually more challenging than a recognition test, such as multiple-choice examinations. However, shared decision-making requires active participation and knowledge of the patients, justifying our approach.¹²

Implication for Research and Practice

Further research should aim at replicating our findings. More specifically, we think that a broad international comparison, focusing on the impact of different healthcare systems on subjects' knowledge, is warranted. How can we explain that a university degree, paramedical training, or greater disease experience does not markedly increase health knowledge? We confirm previous reports showing that health is not coupled with knowledge.⁴ However, unlike previous reports, we show that this phenomenon still prevails in patients with a chronic condition. It seems to be that most people do not inform themselves but still follow social heuristics such as advice taking, imitation, and authorities.

There is an urgent need of better patient education. This brings digital technology into play as we envision that patient-oriented web pages or specialist-moderated internet forums can improve knowledge because most patients with keratoconus are young and therefore digital natives. It also asks for substantial improvement in interdisciplinary patient care and information approach by healthcare actors such as contact lens specialists, primary care physicians, ophthalmologists, and corneal specialists. So far, there are no established collaborations, networks, or common advanced training platforms.

CONCLUSION

Modern management of keratoconus involves patients in shared-decision making and therefore enables patients to face difficult treatment decisions and enhances congruence between pursued treatment options and patient's personal value. It is therefore very important to assess the current knowledge of patients that their treating physician expect them to have. Apparently, there is a substantial mismatch between caregivers' expectations of patients' knowledge and patients' active knowledge regarding their condition. This mismatch may lead to an inefficient care delivery and misunderstandings. The poor level of knowledge calls for concerted educational efforts assuring that patients, particularly those suffering from a chronic condition, can meet their caregivers on equal terms.

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