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Referral pattern and co-management of keratoconus patients in primary eye care: A survey of three European countries

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ABSTRACT

Purpose: To explore current primary care practices in keratoconus management in Portugal and compare with previous reported results in two European countries (the UK and Spain), with a special focus on interdisciplinary collaboration and referral practice patterns.
Methods: An online survey adapted to European professional practice was distributed (via newsletters) by the Portuguese Optometrist Association to explore keratoconus patient management and referral practice patterns among Portuguese practitioners.
Results: Responses of 119 optometrists were compared with previous reported of 464 eye-care practitioners (126 in the UK and 338 in Spain). Most respondents (79% in Portugal, 71% in the UK and 76% in Spain; $p = 0.31$) had < 5 new keratoconus patients each year. No accepted referral criterion was found ($p < 0.01$) because small number of the respondents (14%) in Portugal referred out at initial diagnosis (50% in the UK and Spain); 32% referred out when progression was detected (17% in the UK and 30% in Spain); and a minority (10% in Portugal, 9% in the UK, and 6% in Spain) referred out when visual acuity was affected. A majority of respondents (83%) in Portugal reported no co-management with ophthalmologists (60% in the UK and 73% in Spain; $p < 0.01$).
Conclusion: The results of this study suggest that it is necessary to encourage interdisciplinary collaboration between practitioners to improve referral of patients with suspected keratoconus to an ophthalmology specialist to change the course of this disease, to reduce keratoconus progression and visual acuity impairment and to minimize the impact of this disease on patients' quality of life.

1. Introduction

Eye problems are among the most common consultations in general practice, comprising approximately 5% of consultations in the UK [1]. In most cases, diagnosis, treatment and follow-up are provided by general practitioners, and other diagnoses require a thorough eye assessment by professionals with special ophthalmic knowledge and equipment [2]. Some reports highlight that approximately half of patients with chronic eye diseases do not receive regular eye care by an ophthalmologist [3,4]. One of the most frequent symptoms [1,5] of eye problems is reduced visual acuity; however, this is a nonspecific symptom and could be related to different eye conditions, including refractive errors (uncorrected or due to a refractive change) [2,6]; a chronic eye condition, e.g., cataract, age-related macular degeneration; diabetic retinopathy [2]; or other non-prevalent eye diseases, such as keratoconus, which is commonly diagnosed at puberty or during the second decade of life [7,8].

Keratoconus is a chronic, progressive, bilateral and asymmetric corneal disorder [7,9] that induces a change in patients' refractive error (usually myopia with irregular astigmatism) and impairs visual acuity. This disease has a low prevalence of 1 per 2000 habitants (higher in Asian, Arab and western populations) [7,9,10], but a recent report found a higher prevalence of 1 per 375 habitants in the Netherlands [11]. Keratoconus induces corneal stroma thinning, anterior corneal surface protrusion and irregular astigmatism [7,9] that may result in poor vision even with eyeglasses and spherical or toric soft contact lens (CL). A

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definitive diagnosis requires a complete corneal assessment using a combination of approaches, including corneal topography or tomography (Scheimpflug or optical coherence tomography) and anterior eye biomicroscopy, to identify distinctive clinical characteristics, such as corneal scarring, Vogt's striae, Fleischer's ring, Munson's sign, and/or abnormal corneal thickness spatial distribution [7,9,12].

Keratoconus management is challenging because in early stages, this disease can be undetectable, and standard eyeglasses or CL may allow good visual acuity [13,14]. Moreover, different approaches have been proposed to reduce disease progression and improve patients' quality of life [15,16] (patient education, topical antiallergy or lubricant drops) [9]. If the disease progresses, two main approaches are indicated: special CL fitting (different gas-permeable CL designs are available) for vision rehabilitation [13,17] and a procedure called ultraviolet crosslinking (UV-CXL) to halt keratoconus progression [18] in patients<40 years of age with a corneal thickness greater than 400 μm [9,19]. Finally, approximately 10%–20% of keratoconus patients may require different complex corneal grafting procedures [9,11,19].

In summary, keratoconus patients require a multidisciplinary management approach that involves general practitioners, primary eye care practitioners, optometrists and ophthalmologists. However, the reality of the collaboration between different health care professionals in keratoconus patient management in Europe is unknown because previous efforts have mainly focused on primary care referral patterns of patients with more prevalent eye diseases, such as diabetic retinopathy [20–22] or age-related eye diseases (cataract, age-related macular degeneration) [2,3], with limited information about other chronic eye diseases [20].

The aim of this study was to investigate keratoconus referral patterns in Portugal and compare with previous reported results achieved in two European countries (the UK, and Spain) collecting answers of a large number of European primary eye care practitioners.

2. Materials and Methods

2.1. Questionnaire

An anonymous online survey previously developed and specifically adapted to European primary eye care practices to explore professional practices and attitudes in keratoconus patient management [23,24] was used in this research, with special interest in questions regarding interprofessional collaboration and referral patterns. The questionnaire [24] (Appendix 1) included 17 closed ended questions as follows: eight regarding general CL practice, six focusing on keratoconus management (detection, classification, CL management, etc.) and three concerning patient management and referral practices of interest to general practitioners and primary care practitioners.

2.2. Data collection

The survey was designed with the Google Forms tool (www.google.com/forms/about/) in English, translated to Spanish [24] and to Portuguese for this research, and was distributed by the Portuguese Optometrist Association (UPOOP) in Portugal among local primary eye care practitioners via newsletter that distributed the link to access the online survey. All respondents consented to the use of the data upon answering the survey. The collecting answers were compared with previous reported results in the UK and Spain [24], because the optometry practice is similar in Portugal in the UK and in Spain since optometrists fit CLs in keratoconus patients in the three European countries.

Prior to questionnaire dissemination, one Portuguese experienced CL practitioner reviewed the questions included in the questionnaire to ensure that they were clear, understandable, and relevant to clinical practice in Portugal.

2.3. Data analysis

The SPSS 15.0 (SPSS, Chicago, IL, USA) statistical package for Windows was used to conduct the statistical analysis. Normal distribution of the variables was assessed with the Kolmogorov-Smirnov test ($p < 0.05$ indicated that the data were normally distributed). The mean ± standard deviation (SD) for continuous variables and/or answer percentages for each question summarized the descriptive data analysis. Response frequencies were calculated using cross-tables, and the chi-squared test for ordinal categorical data was used to assess the association between practice variables.

3. Results

3.1. Demographic information

A total of 119 Portuguese optometrists answered the survey and responses were compared with previous reported 464 primary eye care practitioners (115 optometrists and 11CL opticians in the UK and 338 Spanish optometrists) answers [24]. Most of the respondents (58% in Portugal, 73% in the UK and 68% in Spain) had CL experience longer than 10 years.

3.2. Diagnosis and detection of keratoconus patients

Most respondents in all countries (Table 1) detected<5 new patients with keratoconus per year.

In the opinion of the majority of respondents, multiple factors are necessary to suspect that a patient could have keratoconus (Table 1). The main factors referred to include patient history, visual acuity impairment, scissor shadows found during retinoscopy, abnormal manual keratometry results, corneal topography patterns and slit-lamp corneal signs.

The Amsler-Krumeich classification, cone location, degree of severity in three stages (mild, moderate and severe) and Keratoconus Severity Score (KSS) index are the most common keratoconus severity classifications reported by most practitioners with a general consensus about the use of a severity classification in clinical practice (Table 1). Contrary to this finding, only a few respondents confirmed the use of a keratoconus severity classification in their clinical practice (Table 1).

3.3. Contact lenses management of keratoconus patients

A majority of the practitioners considered gas-permeable contact lens fitting to be more complicated in keratoconic eyes than in healthy eyes (Table 1).

3.4. Keratoconus referral practice

Several differences have been found regarding referral patterns to ophthalmologists in the three studied countries (Table 2). Referring to

Table 1
Summary of respondents' answers by country. P = chi-squared value.

	Portugal	UK	Spain	P
Detection of < 5 new keratoconus patients per year	76.3%	70.6%	78.6%	0.31
Multiple factors are necessary to diagnose keratoconus	75.1%	79.4%	73.5%	0.08
Is keratoconus severity classification relevant in clinical practice?	84.6%	67.5%	70.7%	<0.01
Use of keratoconus severity classification	21.4%	7.1%	17.8%	<0.01
Fitting GP CL is more complicated in keratoconus	62.4%	79.4%	80.5%	<0.01
Does not participate in co-management with ophthalmologists	82.9%	60.3%	72.8%	<0.01

Table 2
Stage for considering referring the patient to an ophthalmologist. P = chi-squared.

	Portugal	UK	Spain	P
At initial diagnosis	14.5%	50.0%	50.0%	<0.01
When signs of progression were detected	31.6%	17.5%	29.9%	
If the patient showed a significant visual impairment	10.3%	8.7%	5.6%	
At the patient's request	2.6%	1.6%	2.1%	
No specific time for referral	31.6%	22.2%	12.4%	

an ophthalmologist upon initial diagnosis was common for practitioners in the UK and Spain but not for practitioners in Portugal. Other criteria for referring to an ophthalmologist including detecting signs of progression (between one-third and one-quarter of respondents), if the patient experienced significant visual impairment (answered by<10% of respondents) and at the patient's request (answered by<3% of respondents). Finally, between 10% and 30% of respondents answered that there was no set time for a referral to an ophthalmologist (Table 2).

A large number of respondents (Table 1) did not participate in co-management with ophthalmologists after surgical treatment.

4. Discussion

Keratoconus has a prevalence of approximately 1 per 375 [11] to 1 per 2,000 habitants [7,9], and it highly impacts the patient's quality of life [15,16] because this disease affects young people and induces an impairment in vision that may result in loss of productivity, self-esteem, and difficulties in performing common tasks, such as driving. Furthermore, clinics with a large number of patients have a greater chance of detecting new cases of keratoconus because an age-specific (10–40 years of age) annual incidence of 1:7,500 cases per year has been recently described. [11] Due to the prevalence and incidence of keratoconus, a relatively low number of new cases are expected to be detected by primary care practitioners, including general practitioners and primary eye care practitioners. However, it is difficult to know if all keratoconus patients are detected early in primary eye care practice because the results of this study showed that a large number of eye care practitioners detected <5 new cases each year (78.6% in Portugal, 76.3% in Spain and 70.6% in the UK). Although keratoconus usually develops in late childhood or during adolescence [7,8], a recent report found that diagnosis occurred at a mean age close to 30 years after assessing a larger health insurance database with more than 4 million patients [11]. These results suggest that special attention is necessary in primary eye care practice to improve the early diagnosis of keratoconus, especially in patients with unstable refraction or frequent refractive changes even when visual acuity is minimally affected. A delay in diagnosis increases the risk of vision loss or the need for a cornea transplant, and treatments such as cross-linking can help to halt progression, save patients' vision, and improve their quality of life [15,16,25,27]. Unfortunately, a simple and cost-effective screening test is not currently available for the early diagnosis of keratoconus [27]. Ninety percent of patients referred by primary care practitioners for an eye exam are associated with an acute condition [20], such as a red or painful eye. The most commonly cited reasons for referral were age-related macular degeneration, cataracts, diabetic eye screening, foreign body, glaucoma, and hypertensive retinopathy [20] without a special focus on diseases of low prevalence, such as keratoconus, because efforts are focused on major causes of visual disability in older patients [2,3,20–22].

Most of the major guidelines recommend periodic eye referrals for older adults [2,3], and no specific guidelines have been developed for use in primary eye care to manage or to propose referral patterns for younger patients with suspected keratoconus [20,23]. For example, a minority (14.5%) of the respondents from Portugal referred the patient to an ophthalmologist at the initial diagnosis compared with half of the respondents from the UK and Spain [24], which are higher than previously reported (7.8%) by Australian eye care practitioners [23]. However, approximately one-third of respondents in Portugal and Spain but close to 20% in the UK [24] prefer to refer patients when keratoconus progression is detected, which is less than a previously reported referral pattern [23]. This referral pattern differs from the American Academy of Ophthalmology recommendations which suggest avoiding referral whenever possible and waiting to refer keratoconus patients when the vision cannot be improved with eyeglasses or CL or when progression is confirmed [27]. However, the referral criteria found in this study could cause a large number of patients to not receive appropriate treatment to halt keratoconus progression (such as cross-linking), which could result in a significant loss of vision. In fact, the Global Panel of Keratoconus and Ectatic Diseases [9] recommends different management options to halt keratoconus disease in the early stages, including pharmacological and nonpharmacological treatments, to reduce the impact of keratoconus on patients' quality of life [15,25].

For example, in the early stages, the management options for keratoconus patients include patient education to avoid rubbing one's eyes; preservative-free topical lubricants to reduce ocular irritation; and topical antiallergy treatment in atopic patients or with a history of asthma, eczema, and hay fever with the aim of halting disease progression [9]. All of these options can be provided by primary health practitioners [2] or co-managed with dermatologists and/or allergists [27]. At this stage, eyeglasses and/or soft CL with a toric (astigmatism) design could be necessary to provide good visual acuity [13,14].

Cross-linking (UV-CXL) treatment increases the biomechanical stability of the cornea and its rigidity to halt keratoconus progression [18] when clinical progression is documented [9] in patients younger than 40 years of age with corneal thickness greater than 400 μm [9,19]. This treatment could help to save patients' vision, especially in early stages when patients could exhibit satisfactory vision with eyeglasses or spherical or toric contact lenses. Therefore, it could be necessary to improve the percentage of practitioners who refer keratoconus patients upon initial diagnosis (<15% in Portugal but half in the UK and Spain [24]; Table 2) to improve keratoconus patient care and reduce disease progression and vision impairment.

If keratoconus patients achieve unsatisfactory vision using eyeglasses or standard CL, fitting rigid gas-permeable CL for visual rehabilitation could be recommended [9] (several designs are available, such as corneal gas-permeable lenses with a specific design for keratoconic eyes and hybrid, semiscleral or scleral CL) [13,14,28]. Gas-permeable CL significantly improves keratoconus patients' quality of life [25]; however, fitting CL in keratoconus patients is challenging and often requires long practitioner time and patient chair time [24,29,30]. Finally, if patients have CL intolerance or unsatisfactory vision with eyeglasses and/or CL, different surgical approaches have been proposed, including intrastromal corneal ring segments (ICRS), anterior lamellar keratoplasty (ALK), descemetic deep ALK (dDALK), and penetrating keratoplasty (PK) [9,11,19].

All of these management options could be relevant to primary eye care practitioners because they have a paramount role in reducing vision impairment, as they are the first contact between patients and the health care system [2,31]. Moreover, an effective interdisciplinary collaboration between health care professionals in both primary and secondary health care is necessary to provide better management of keratoconus patients [2], to preserve patients' vision, and to improve patients' quality of life [15,16,25–27]. Because this condition is a relevant public health problem, collaboration could reduce the economic burden of keratoconus patient management [27].

However, a higher rate of Portuguese respondents (83%) did not participate in co-management with ophthalmologists was observed in this survey compared with 73% of respondents in Spain and approximately 60% of respondents in the UK [24], or with 43% of eye care practitioners in Australia [23]. These results suggest that it is necessary to improve patient co-management between practitioners in primary and secondary care. Additionally, adopting best practices for optimizing

the treatment of keratoconus patients would improve their vision and quality of life. Some eye referral barriers between primary care practitioners and secondary specialists have been previously described, suggesting that it is necessary to improve communication and feedback between practitioners [20]. This study results could help to improve eye care, promote effective collaboration and communication between different practitioners, and encourage patient compliance to enhance patients' vision and quality of life [2].

The characteristics of respondents (for example, participation limited to primary eye care practitioners or the respondents' ability to diagnose keratoconus) and the relatively low number of answers received could be the first limitation of this study. However, the participation was slightly higher to previous surveys given to health care practitioners, with a response rate close to 3% of registered practitioners in Portugal (<1% in the UK and 2% in Spain) [21,23,31]. Second, the use of an anonymous online survey may make it impossible to know the exact completion rate between all possible practitioners. Finally, the questionnaire was not disseminated to general or primary care practitioners because referral practices in primary care have seldom been examined previously, and reports mainly have focused on the referral for high-prevalence eye diseases (such as age-related macular degeneration or glaucoma) [3] or diabetic patients [20], without a focus on infrequent chronic diseases in young people, such as keratoconus. However, this is the first time that current primary eye care practice has been related to keratoconus disease in three different European countries (Portugal, the UK and Spain [24]) where the optometry practice is similar (primary eye care and prescribing contact lenses in healthy and keratoconus patients). These results highlight the necessity of improving interdisciplinary collaboration in the management of keratoconus patients. Additionally, a reasonable consensus regarding the lack of clinical guidelines for management and referral of these patients was found in the respondents from Portugal and compared countries (Table 2) [24].

In conclusion, the results of this study provide evidence that current primary eye care management of keratoconus patients in Portugal needs to be improved. Encouraging interdisciplinary collaboration is essential to changing the evolution of keratoconus, helping to prevent vision impairment and keratoconus patients' functionality and improving current referral of suspected keratoconus patients to an anterior segment specialist (ophthalmologist).

Keratoconus patient care could be improved with early detection and specialist referral for a definitive diagnosis. Non-surgical management, including patient education (avoiding rubbing eyes), antiallergy treatment (in allergy and atopic patients), preservative-free topical lubricants to reduce ocular irritation, gas-permeable CL (for visual rehabilitation) and surgical options including cross-linking (to halt disease progression) and/or other surgical techniques (intrastromal corneal ring segments, different anterior lamellar keratoplasty techniques and penetrating keratoplasty), are necessary in the management of these patients. These options require multidisciplinary collaboration between general practitioners, primary eye care practitioners and ophthalmologists to guarantee better eye care to these patients, minimize keratoconus progression, reduce visual acuity impairment, and improve patients' quality of life.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.clae.2021.101518.

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