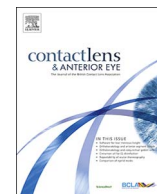




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Patient-related barriers to Rigid Gas Permeable (RGP) lens wear among keratoconus patients in Jordan

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ABSTRACT

Purpose: To assess potential patient-related barriers to rigid gas permeable (RGP) lens wear for vision rehabilitation in a sample of keratoconus (KC) patients in Jordan.

Methods: Barriers for RGP contact lens wear among KC patients were discussed and specified by a focus group which consisted of five optometrists who are involved in contact lens practice. The focus group addressed potential barriers for RGP lens wear from the patient's perspective. The identified barriers were then used to design the final questionnaire used in the study. The questionnaire consisted of 8 questions which ask the participant to rate, within a 5-points scale (1: strongly disagree to 5: strongly agree), how each suggested item is considered a barrier for RGP lens wear.

Results: 204 KC patients (86 females, 118 males) were involved in a semi-structured interview to answer the questionnaire. The average age of participants was 30.85 (\pm 8.74) years old and ranged from 18 to 62 years. The average age of diagnosis of KC (\pm standard deviation) is 21.96 (\pm 7.22) years old with a range of 12–52 years. All participants reported that they had never tried RGP lenses for their vision rehabilitation; however, other management options were reported such as glasses, keratoplasty, collagen cross linking and Intacs. The mean score of total barriers to RGP wear was high at 3.8 (\pm 0.4) (out of 5). The major identified barriers were: lack of awareness of the benefits of RGP lenses, fear of possible lens complications, lack of medical insurance and high cost of the lens.

Conclusions: The study reveals that several barriers were identified as prevalent. Consequently, there is an imperative need to adopt better planning strategies for management protocol of KC in order to assure best eye care service for KC patients in Jordan.

1. Introduction

Keratoconus (KC) is a bilateral asymmetrical non-inflammatory disease that affects the cornea. The disease is characterized by progressive ectasia and thinning of the cornea, which induces myopia and irregular astigmatism. Such change in the refractive state of the eye could result in a reduction in visual acuity and visual performance [1].

The prevalence of KC has been reported in many countries around the world, with a range between 50 and 230 per 100000 [1–12]. According to Hashemi et al., [5] the disease has been found to be more prevalent in Asia and the Middle East in comparison to western countries. Hashemi et al. also reported that this observation was primarily due to factors attributed to family history; mainly consanguineous marriages which are more common in Asia and the Middle East. To elaborate, similar results were found in Jerusalem where the prevalence of KC was also high, with this prevalence attributed to family history,

male gender and atopy [12]. Although there is a lack of reports about the prevalence of KC in Jordan, it is expected that the actual prevalence of KC is as similarly high as in other countries in the Middle East. This is based on the high prevalence of positive family history of KC among KC patients and repeated inter-family (consanguineous cousin) marriages within several communities in Jordan. A higher rate of genetic diseases is commonly connected to communities where inter-family (consanguineous cousin) marriages are common. In addition to genetic factors, the arid climate which characterizes Jordan may also contribute to a high prevalence of the disease. Finally, the high occurrence of atopy and ocular allergies in Jordan [13] may also be associated with an increased risk of KC among affected patients [14].

Depending upon the severity of the disease, different options of KC management are available. Spectacles and contact lenses are considered the primary optical management options of the disease. In addition to optical management options, there are surgical management options

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which include corneal collagen cross-linking, intra-corneal ring segments (Intacs) that are recommended in the mild and moderate stages of KC, and corneal grafting which is considered in more severe cases when vision highly deteriorates as the disease progresses [1].

It is widely acknowledged that rigid gas permeable (RGP) contact lenses are the most appropriate non-surgical method for the management of KC patients. These lenses provide better visual quality as they enhance the regularity of the corneal surface; thus providing maximum visual acuity [15]. In comparison to other forms of contact lenses (e.g. soft hydrogel and silicone hydrogel), RGP lenses are the most commonly used lenses among KC patients [15–18]. These lenses are available in different designs that are capable of correcting the high levels of irregular astigmatism in the keratoconic cornea through the creation of a smooth optical refracting surface between the cornea and the lens [15]. Several reports show that the use of these RGP lenses delay the need for surgery in the majority of KC fittings [16,19].

In Jordan, ophthalmologists provide clinical diagnoses of KC on the basis of clinical examination; this examination includes slit-lamp assessment and Videokeratography. Once the diagnosis is confirmed, the management options are discussed. The patient then has the freedom to decide which management option (if any) to follow. However, it is often noted that there are no clear management guidelines for the disease, with the KC management protocol varying between ophthalmic clinics, especially between clinics in public and private hospitals. For instance, most public hospitals are not equipped to fit RGP contact lenses. This makes spectacle and surgical intervention (covered by the government's health insurance) the main options of KC management in these hospitals. On the other hand, private hospitals which are well-equipped for RGP lens fitting apply a different protocol for disease management, and this protocol includes RGP lens intervention. Therefore people who visit private clinics for consultation and treatment have the option of fitting RGP lenses, which are not covered by the government's health insurance. Regrettably, there is no well-defined pathway that allows the referral of KC patients to other clinics or places that fit RGP lenses in Jordan; instead, the patient might be referred to a contact lens specialist by a private recommendation from family or friends.

Despite the expected high prevalence of the disease in Jordan, it is found that the number of KC patients who are referred to contact lens clinics is still limited. This observation could imply the existence of barriers to RGP lens fitting in KC patients in Jordan.

This study aims to assess potential patient-related barriers to RGP lens wear for vision rehabilitation among a sample of KC patients. The study also provides recommendations to improve KC management and quality of life among affected KC patients in Jordan in light of the information gathered in the study.

2. Methods

2.1. Study design and participants

A cross-sectional survey design was used to identify barriers to RGP contact lens wear among KC patients in Jordan. The research tool involved an interview-based questionnaire that addressed a sample of patients who were clinically diagnosed with KC and have not been fitted with RGP contact lenses before. The sample group of the study involved patients visiting ophthalmology clinics and optometry practices in Jordan. All the patients who participated in the study had a confirmed clinical diagnosis of KC by ophthalmologists at the time of the study, and were under ongoing care. The researchers could not determine the clinical characteristics of KC patients because they did not have access to the patients' medical records.

A snowballing sampling strategy was employed to arrange meetings with KC patients at a primary eye care clinic affiliated to Jordan University of Science and Technology (JUST). Several patients willingly led the researchers to other KC patients who were eager to participate.

2.2. The questionnaire

The barriers questionnaire was developed by the research team for the purpose of this study. The first step of designing the questionnaire involved a focus group discussion to design the research questionnaire. The group consisted of five qualified optometrists who are involved in contact lens fitting and research. Barriers for RGP contact lens wear among KC patients were discussed, verified and documented. All the highly rated barriers were considered and incorporated within the design of the final version of the questionnaire which tentatively listed 10 barriers. Following up from discussion, a list of potential barriers to RGP lens wear was drafted in the form of Likert-scale questionnaire. Then, by means of a semi-structured interview, participants were asked to rate how much they perceive each item as a barrier (from 1: strongly disagree to 5: strongly agree).

The next step involved conducting a pilot study on a group of ten KC patients to examine the consistency and readability of the questionnaire questions. It was found that two items (barriers) in the questionnaire were not correlated and were hence removed. As a result, eight items were retained in the final version of the questionnaire. The data from the patients' responses were based on their level of agreement with each statement in the questionnaire. If the patient agreed or strongly agreed with a barrier, this response will be recorded as an identified barrier. The five point scale was split into three sub-categories for the sake of simplicity and better comprehension; these categories were as follows: Agreed and strongly agreed (means 'it is a barrier'), neutral (undecided if it is a barrier or not), and disagreed or strongly disagreed (means 'is not a barrier').

For scoring purposes, the total barrier score was computed by adding together the respondents scores on each individual barrier and dividing by 8 (the total number of barrier questions). The total score ranged from 1 to 5, with the barriers considered to be increasing as the total score increases.

In addition to questions relating to barriers to RGP use, basic demographic information and characteristics of patients were also collected. Those included: age, gender, education, monthly income, family history of KC, working status, and age at the diagnosis of KC.

The purpose, methods and significance of the study were explained to participants prior to their interviews by a trained interviewer. The time required for the completion of the semi-structured interview and answering the questionnaire ranged between 15 and 20 min for each participant.

It is vital to emphasize that the main reason for using a semi-structured interview was to ensure the patients' comprehension and interpretation of the questions; and this in turn would guarantee obtaining conscientious responses and avoiding the missing of data.

A research assistant helped in conducting the semi-structured interviews by explaining to the participants the questionnaire questions. This procedure ensured that each participant (KC patient) had the same level of comprehension of the task in hand, and it establishes the consistency of the data collected as revealed in the results. Additionally, the research assistant helped some respondents with visual impairment and illiteracy, which may affect their reading ability of the questionnaire.

2.3. Statistical analysis

Data were analyzed using the Statistical Package for Social Science (SPSS, International Business Machine Corp. IBM) version 21. Descriptive analysis was used to calculate frequencies, percentages, means and standard deviations. Frequencies and percentages were calculated to summarize categorical and nominal data. Bivariate analysis was conducted using Man-Whitney *U* tests.

2.4. Ethics approval

The ethics approval for conducting the study was granted by the

Table 1
Demographic characteristics of keratoconus patients. (n = 204).

Variable	Frequency (%)
Gender	
Female	86 (42.2)
Male	118 (57.8)
Education	
High school education or less	96 (47.1)
Higher education	108 (52.9)
Age at diagnosis with KC	
12–18 years	79 (38.7)
19–25 years	74 (36.3)
26–33 years	35 (17.2)
34–45 years	15 (7.40)
More than 45 years	1 (0.50)
Family History of KC	
Yes	86 (42.2)
No	118 (57.8)
Occupation	
Working	107 (52.5)
Not working	97 (47.5)
Monthly income	
Low	171 (83.8)
High	33 (16.2)

Institutional Review Board (IRB) committee at Jordan University of Science and Technology. The study has been conducted in accordance with the declaration of Helsinki of 1975, and its later amendments. Verbal informed consent was obtained from all individual participants prior to their participation in the study.

3. Results

A total of 204 patients (86 females, 118 males) who have a clinical diagnosis of KC were interviewed. All patients had no previous RGP lens intervention at the time of the recruitment in the study, and none of them have tried RGP lenses before.

The average age of the study sample was 30.85 (\pm 8.74) years, and ranged from 18 to 62 years. The average age of diagnosis of the disease (\pm standard deviation) is 21.96 (\pm 7.22) years with a range of 12–52 years. Within this study sample, 153 patients (about 75%) were diagnosed with the disease between the ages of 12 and 25. The information and characteristics of all participants are shown in Table 1.

Responses obtained from the semi-structured interviews shows that 97.5% of the patients have already heard about contact lenses for refractive error correction. However, 34.8% of the patients reported that they have no specific information about RGP contact lenses and their role for vision correction in KC. Remarkably, the entire sample (100%) reported that they had never tried RGP lenses for their vision rehabilitation. Moreover, they confirmed that they do not have any self-reported contraindications for contact lens wear; such as severe dryness, allergies and active ocular surface disease. When the participants were asked about the level of visual impairment caused by the KC, all patients reported that their vision is affected by the disease.

The data showed that more than half of the patients (59.31%) are using spectacles as the main management option for their vision correction. Fig. 1 shows the results of the current method of management of KC as reported by patients in the study.

The mean of the total barriers score for RGP wear was high at 3.8 ± 0.4 (out of 5 the maximum score). The major identified patient-related barriers to fitting of RGP contact lenses were the lack of awareness about the benefits of RGP lenses and the fear of lens possible complications. These two barriers were reported by 90.2% of the patients. The lack of medical insurance that covers the lens cost was identified as the second barrier, and it was reported by 89.7% of the patients. The least reported barrier by patients (16.2%) was socio-cultural beliefs such as: the disease is ‘God’s will’, or ‘being afflicted by

illness means that you are closer to God’. Table 2 presents all items of the questionnaires and the aggregate participants’ responses to each item.

The Mann-Whitney U Test was conducted to examine the existence of any significant difference in the total barriers score with respect to participants’ background characteristics.

None of the variables (family history, monthly income, gender and level of education) showed any significant difference on the perceived barriers to RGP wear ($p > .05$) except for their working status ($U = 4044$, $p = 0.006$). Non-working participants (Mean Rank = 114.3) perceived a higher level of barriers than working participants (Mean Rank = 91.8). In addition, participants with low family monthly income (Mean Rank = 108.3) reported significantly higher levels of barriers than those of high family income (Mean Rank = 72.7) participants ($U = 1836.5$, $p = 0.001$).

4. Discussion

Vision impairment from KC can be managed by many optical options. RGP contact lenses are considered one of the most common rehabilitative optical treatments that aims to correct corneal irregularities caused by the disease [15].

This study shows that RGP contact lenses fitting is a neither frequent nor a familiar choice of KC management in Jordan. This is remarkably regrettable because of the expected high occurrence of the disease among the population. It is found that KC was responsible for 5% of both unilateral and bilateral blindness among adults aged over 20 years [20]. In addition, KC was reported as a common cause of penetrating keratoplasty treatment in Jordan in the years 1979–1998, with the disease accounting for 65.6% of all keratoplasty cases during that era [21].

In their report, Efron et al. examined the trends in rigid contact lens fitting during a 5-year period (2007 to 2011) in 40 countries including Jordan, and they found that the rate of global utilization of RGP lenses was 10.8% of all contact lens fits [22]. According to their report, RGP lens utilization in Jordan was reported as 6%, a rate remarkably lower than other places in Asia for the same study such as: Malaysia (37%), Japan (21%) and Israel (17%) [22].

In the International Contact Lens Prescribing report in 2016, Morgan et al. reported an average utilization rate of RGP lenses of 9% in 30 countries [23]. However, Jordan was not included in this report. The utilization rate of RGP lenses in Jordan was reported by a recent study by Haddad et al. (2016) who found that RGP lens fitting accounted for 8.4% of the fits in the Jordanian market in 2015 [24]. In the aforementioned study, the reported rate of utilization of RGP lenses was not exclusively for KC cases, but also included RGP lenses in other cases; such as: high refractive errors, high astigmatism, orthokeratology; and in cases of other corneal irregularities; such as: post keratoplasty, keratoglobus and pellucid marginal degeneration.

In light of the researchers’ personal clinical experience with KC in Jordan, it is believed that the number of patients who are diagnosed with KC and assessed for suitability for RGP lenses is not equivalent to the actual take-up of RGP lenses in KC patients. This implies the existence of barriers to RGP lens fitting in KC patients in Jordan.

One of the main goals of this study is to assess KC patients’ barriers to RGP lens fitting in Jordan in the light of the expected low uptake of RGP lenses as an option for vision correction in KC cases. Herein, the findings of this study could help in identifying potential barriers which will facilitate outlining strategies in the management of KC disease in the region.

The study reveals that the majority of the sample showed a presentation of KC at an age younger than 25. This finding agrees with previous research which reports that the disease primarily develops in youth [7–9].

However, the current study disagrees with findings from the Collaborative Longitudinal Evaluation of Keratoconus (CLEK) study,

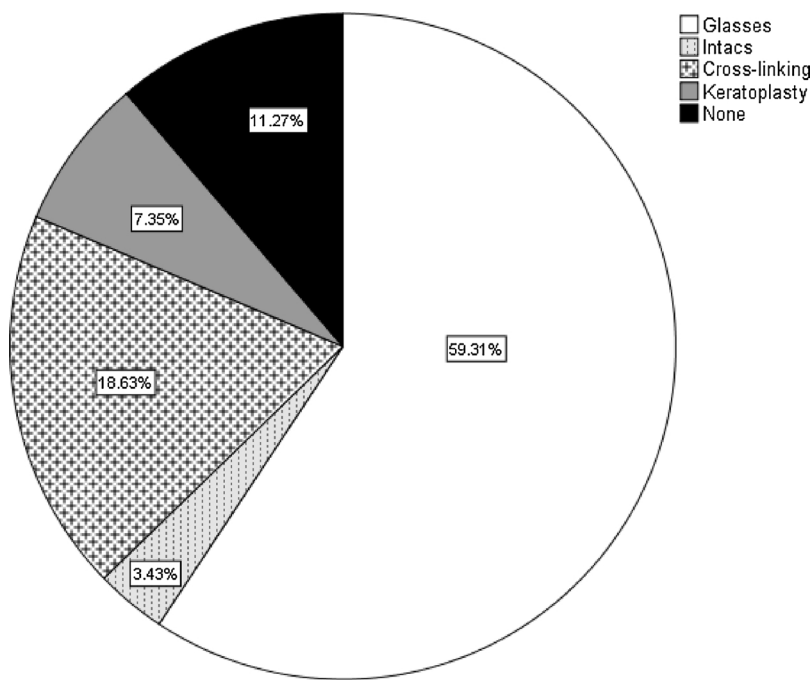


Fig. 1. Current management of keratoconus among study population (n = 204).

Table 2
Responses for potential barriers to RGP contact lens wear represented by patients' levels of agreement.

Barrier	Agree Frequency (%)	Neutral Frequency (%)	Disagree Frequency (%)
High cost of the lenses	161 (78.9)	11 (5.4)	32 (15.7)
Ophthalmologists' referral to alternative ophthalmological treatment options such as Intacs, cross linking or keratoplasty based on	153 (75)	22 (10.8)	29 (14.2)
Lack of awareness of benefit of RGP lenses in vision rehabilitation in KC.	184 (90.2)	14 (6.9)	6 (2.9)
Fear of contact lens insertion and removal	149 (73)	17 (8.3)	38 (18.6)
Fear of contact lens possible complications	184 (90.2)	7 (3.4)	13 (6.4)
Socio-cultural believes such as: the disease is God's will or having an illness means you are being closer to God	33 (16.2)	26 (12.7)	145 (71.7)
Accessibility to health care service e.g. living in remote areas and lack of transportation.	102 (50)	7 (3.4)	95 (46.6)
Lack of medical insurance to cover lenses cost	183 (89.7)	5 (2.5)	16 (7.8)

that revealed that the majority of Americans who were first diagnosed with the disease were over the age of 20 years [25].

The current study showed that more male patients (57.8%) were affected with KC than female patients, and this coincides with similar findings regarding the preponderance of male KC patients [6–9,14,25,26].

Remarkably, the current study demonstrated that a significant percentage of the patients (42.2%) have had some of their relatives diagnosed with KC; and thus, they have had a family history of the disease. Accordingly, there is evidence of genetic predisposition of KC in Jordan.

The early onset of KC among the study sample may also suggest the hypothesis of genetic and environmental factors; such as environmental damage due to high levels of UV light exposure [27].

Several barriers have been identified as common among the study sample. For instance, the low level of awareness of RGP lens benefits in KC management was a major barrier to fitting RGP lenses. This barrier reflects the KC patients' insufficient knowledge about the disease and its management. Barriers attributed to a lack of patients' awareness regarding the benefits of RGP lenses must be efficiently addressed to increase successful RGP intervention in KC. Such intervention should involve providing a more intensive education to patients about RGP lens intervention in terms of material, modalities and benefits.

As the patient's information about RGP lenses is principally obtained from optometrists, other potential sources of information such as general practitioners and mass media should be enhanced as well. The

researchers have perceived how information related to contact lenses, and RGP lenses in particular, are not well advertised in Jordanian written and visual media. What is more, local media, especially newspapers and television, shows prevalent bias in their occasional coverage of KC care. This is mostly manifested through its extensive reporting of ophthalmic services and achievements of surgical treatments of KC.

On the other hand, social media is capable of educating patients regarding health care, in addition to its function as a marketing tool for new services. Patients can benefit from social media in health care through education, networking, performing research and receiving support from the society [28]. However, the researchers have analyzed social media, such as Facebook and Twitter, and searched for pages or blogs concerned with the presentation of KC in Jordanian society, but their search has yielded no results. This could be due to cultural considerations which obstruct KC patients, or their families, from talking about the disease and associated vision impairment in public.

Fear of possible complications from wearing contact lenses was also highly reported as a barrier among the study sample. The reported fear of contact lenses was toward contact lenses in general, and does not subsequently imply awareness of RGP lenses. There are many references regarding the potential impact of KC on patients' emotional wellbeing, and this factor could affect their ability in taking decisions [29–31].

For instance, research investigating the impact of KC on the patients' quality of life reveals how KC patients show more fear and anxiety than those who do not have the disease [31].

Furthermore, several studies which were based on the National Eye Institute-Visual Functions Quality Questionnaire (NEI-VFQ-25) (addresses the impact of KC on patients' quality of life) revealed that the disease results in lower social functioning, mental health, role difficulty and dependency among affected patients [29–31].

The high cost of RGP lenses and the lack of governmental health insurance or subsidized medical services which cover the lens cost is another important barrier reported by patients. For this reason, unemployed and low-income patients were more likely than other patients to report the cost of the lenses as a decisive barrier for use, with the lens cost can range from 200 to 400 dollars per lens. The cost barrier is found to be indirectly associated with another minor barrier reported by patients, which is the inaccessibility and inefficiency of the transportation system that allows access to providers of health care services. Travel expenses add considerable value to the lens costs, to the extent it prevents ordinary patients (whose monthly income is less than 500 dollars), from benefitting from the lenses. Moreover, the progressive nature of the disease, and its association with changes in corneal curvature, requires the patient to repeatedly change RGP lenses, and this imposes an additional financial burden on the patient. Therefore, the cost barrier could force patients to resort to cheaper alternatives such as spectacles or soft contact lenses to correct their vision impairment. In addition, patients who enjoy specific types of medical insurance are able to obtain surgical treatment, which is a more permanent solution.

Most ophthalmology departments in Jordanian public hospitals are not equipped to fit RGP contact lens. These departments lack optometry clinics and contact lens specialists. For this reason, contact lenses fitting services, including RGP lens fitting, are only provided by hospitals or optometry practitioners in the private sector. Unfortunately, prescribed RGP lenses are not covered by any type of governmental medical insurance because they are considered cosmetics rather than a treatment option.

Ophthalmologists' referral to other surgical interventions was also perceived as a highly identified barrier by KC patients. According to patients, most ophthalmologists prefer surgical interventions, such as Intacs and keratoplasty, because these profitable surgical options serve the ophthalmologists' financial interests; especially if these surgical interventions are performed in private clinics and hospitals.

Another problem with KC management in Jordan is the fact that the clinical protocol for KC management is ill-defined. The protocol followed by the public hospitals (administered by the Ministry of Health (MOH)) is different from that of the military hospitals (administered by the Royal Medical Services (RMS)). Moreover, the protocol followed by the private hospitals is different too. To elaborate, it is found that the RMS is the only medical care provider that presents RGP contact lens fitting to all its KC patients before any surgical intervention. However, the RMS restricts its health care services to army staff and the civilian employees in the national army and their families.

Fear of insertion and removal of RGP lenses is another barrier that discourages KC patients. This barrier may be attributed to the possible impact of the disease on the emotional wellbeing of the affected patients as discussed earlier.

Furthermore, this type of fear may be attributed to the description of these lenses as *Salba* ('rigid' or 'hard' in Arabic), and this results in an anxiety of inserting something hard or rigid into the eye. The naming issue has drawn the attention of experts in the International Association of Contact Lens Educators (IACLE) who recommended avoiding the use of such terms when describing gas permeable contact lenses.

Almost half of the participants reported that inaccessibility to health care services due to living in remote places, and lack of transportation, is another important barrier. However, this barrier might be directly related to the cost barrier that discussed before as living in remote places may add additional costs to the lenses.

Finally, the least identified barrier in this study was the effect of socio-cultural beliefs; such as that disease is God's will, or having an illness makes you closer to God. The low presentation of such a barrier

implies a high level of cultivated awareness among both observant and non-observant Muslims. Most Muslims do believe that cure should be asked from Allah first, and then be sought by the medical treatment provided by the experts.

The above discussed barriers require a more elaborate referral and management protocol for affected patients, and they accentuate the need for better communication between ophthalmologists and optometrists to ensure they are providing the best eye care service for their patients. Moreover, the current study draws attention to the insignificant contribution of optometrists in the management of KC. The marginalized role of optometrists in patients' referral to RGP lenses can be attributed to the fact that optometry profession in Jordan is dominated by ophthalmologists. An evident manifestation of this dominance is that regulations, exams, licenses of practicing the optometry profession are all implemented and administered by ophthalmology boards assigned by the Ministry of Health in Jordan.

5. Conclusion

RGP fitting is an underestimated choice in vision rehabilitation of KC patients in Jordan. This is deduced from the several reported barriers by the KC patients in this study. By addressing these barriers, the researchers aim to increase the success of RGP intervention in KC. Subsequently, this will help in better management of KC disease in Jordan and will improve vision related quality of life among affected patients.

It is recommended that KC management be listed as a priority in the national plan for eye care in Jordan. Furthermore, there is a demand on the health care system in Jordan to install specialized contact lenses clinics. Such clinics will broaden the spectrum of the optometry profession to encompass both public and private hospitals. These measures would make lens fitting services available, accessible, and professionally practiced, in all Jordanian hospitals.

5.1. Limitation of the study

It is believed that the disease severity and patient's visual acuity are important measures that may affect the patients' decision to wear RGP lens, and this could result in a medical decision that favors other management options of KC. In this study, the sample of the KC patients was interviewed without any further ocular examination prior to the study. Furthermore, patients' medical records were not accessible to the researchers at the time; neither before nor during the study. Thus, KC severity and visual acuity of the patients were not assessed in this study.

Conflicts of interest

The authors declare that no competing interests exist.

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