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Demographics of older keratoconics in Wales and their mortality rates—Where are the older keratoconics?

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ABSTRACT

Aim: The aim of this study was to identify keratoconics at least 40 years of age attending Welsh optometric hospital services, look at their demographics and mortality rates, and test the hypothesis that they die earlier than the general population.

Methods: Keratoconic patients born before 1972 were identified retrospectively through contact lens services across 5 hospitals in Wales, United Kingdom. Patients' notes were reviewed to confirm the diagnosis and collect demographic data. The Exeter patient registration system was used to trace if patients were deceased or alive. General population data was obtained from the Office for National Statistics.

Results: A total of 202 keratoconics at least 40 years of age were identified. The mean age was 50.8 years, 62% of patients were male and 97% Caucasian. Mean age at diagnosis was 28.7 years. Two patients were deceased, one died in 2012 and one in 2013. In 2012 mortality rates for studied patients and the general populations were 0.005 and 0.019, respectively ($p = 0.03$).

Conclusions: Mortality rates for the identified keratoconics were found to be significantly lower than the mortality rates for the general population in 2012. Collected data represents 52% of expected keratoconics over the age of 40, calculated based on disease prevalence, study inclusion criteria and population numbers within the regions included in the study. Thus suggesting the reason for lack of older keratoconics in the National Health Service optometric clinics could be non-attendance rather than higher mortality rates.

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1. Introduction

Clinical observations and literature reports show a consistent lack of older keratoconics in both ophthalmic and optometric practices [1]. Moodaley et al. [2,3] looked at mortality rates for keratoconics attending Moorfields Eye Hospital between 1972 and 1982, and found no significant difference between mortality rates in this group versus the general population. However studied sample was relatively young with 76.6% of patients between 40 and 50 years of age. One of the explanations for the lack of older keratoconics in Moorfields' clinics was that older, more stable patients no longer travel to a tertiary centre for their ophthalmic care and attend hospitals closer to their homes [2]. Study reported herein was designed to look at demographics and mortality rates of

older keratoconics living in Wales, a more geographically stable population compared to London. [4] The aim was to provide an explanation as to what happens to the older keratoconics in the National Health Service (NHS) hospital optometric practices by comparing the mortality rates of identified patients and the general population.

2. Methods

The National Institute for Social Care and Health Research ethics committee granted approval for the study in 2012. Five Welsh NHS hospitals were included, with 3 covering the whole of the North Wales area and 2 covering 2 major cities in South Wales (Table 1), caring for a population of 1,278,560 [4]. Keratoconics 40 years and older in 2012, that is born before 1972, were identified retrospectively through contact lens clinic records at all 5 hospitals. The same age criteria were chosen to allow comparison with the Moodaley et al. study. Data was collected from the year of setting up of the optometric services until 2012. All case notes were

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Table 1
Number of patients at each NHS hospital included in the study.

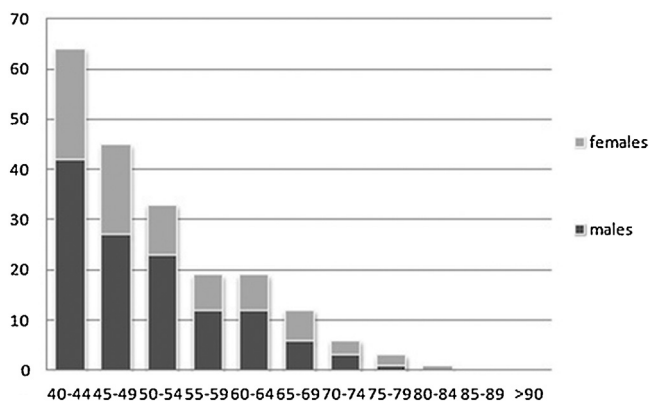
| Hospital | Number of patients identified at each site |
|--|--|
| Stanley Eye Unit in Abergele | 78 |
| Wrexham Maelor in Wrexham | 30 |
| Ysbyty Gwynnedd in Bangor | 37 |
| Univerisity Hospital of Wales, Cardiff | 23 |
| Singleton hospital, Swansea | 35 |

reviewed to confirm the diagnosis, age at diagnosis, ethnicity and follow up period. Due to the historical data retrieval, diagnosis method varied from typical slit lamp findings with changes on keratometry and/or keratometry for patients seen from 1970 to 2000, and from 2000 to 2012 based on the use of video-keratography. Only patients with a diagnosis confirmed by consultant ophthalmologists were included in the study. All keratoconics at least 40 years of age were included in the study; both actively attending and no longer attending patients. Patients with keratoconus and Down's syndrome were excluded, since their average life expectancy is 58 years of age [5] and they have poor success with contact lens wear [2]. The Exeter patient registration system was searched for deceased patients based on their name, date of birth and hospital numbers. All statistical data including population numbers, mortality rates and geographical stability for the general population in Wales were obtained from the Office of National Statistics for year 2012, the same year as identification of the keratoconus sample was completed. Statistical analysis was carried out using SPSS 20.0 and inferential tests used were Fisher's test, Mann Whitney *U* test and Spearman's rho correlation.

3. Results

A total of 202 keratoconics over 40 years of age were identified. Mean age was 50.8 ± 9.6 years with 46% of the sample older than 50 (Graph 1). Positive correlation for the age distributions between identified patients and the general population in Wales over 40 (Spearman's rho 0.9) was found. One hundred and twenty six (126) patients were males and 76 females, with 97% identified as Caucasian and 3% Asian. Mean age at diagnosis was 28.7 years (data available for 51% of patients), with males diagnosed on average 3 years earlier than females (p 0.6). Follow up data was available for 39% of patients and covered a mean period of 10.9 ± 8.45 years.

Two out of 202 patients were found to be deceased through public health patient registration system. The identification

**Graph 1.** Age distribution of male and female keratoconics.

process was complete at the end of 2012, and the data on mortality was searched for in 2013 identifying 1 male patient who died at the age of 62 in 2012 and 1 female who died at the age of 72 in 2013. Mortality rates for over 40 year olds living in Wales from the Office for National Statistics was obtained for year 2012, same year that sample identification was complete. To compare the mortality rates of studied patients with the mortality rates for the general population in Wales in year 2012, the patient who died in 2013 was excluded from analysis. The mortality rate for identified keratoconics in 2012 was 0.005 versus 0.019 for the general population (p 0.03) [4]. Causes of death were not available as part of the public health mortality search. Theoretical calculations using population numbers of people over 40 living in Wales in 2012 [4], prevalence of keratoconus of 54.5 per 100,000 [6] and contact lens requirement of 74% [1], established number of expected keratoconics over 40 in the areas covered by the study to be 382.

4. Discussion

Earlier mortality of keratoconics has been debated as a likely explanation for the lack of older keratoconics in clinical practice, especially given the associations of keratoconus with systemic connective tissue disease, mitral valve prolapse, floppy eye lid syndrome and sleep obstructive apnoea as well as more recent reports of potential link with obesity [1]. Keratoconic patients undergoing penetrating keratoplasty tended to be more obese than patients needing the same surgery for different indications [7,8]. The causative relationship between aforementioned systemic conditions and keratoconus have not been proven, however that does not exclude their potential to contribute to earlier mortality in keratoconic patients.

Most studies show relative under-representation of older keratoconics, which adds to the mystery as to what happens to older keratoconics in ophthalmic and optometric practice [1]. The 1998 Collaborative Longitudinal Evaluation of Keratoconus (CLEK) study only included 15% of patients over 49 years of age with proportionally bigger number of patients between ages of 50 to 59 compared to over 60 year olds [9]. The 1992 Moodaley et al. study included 23.4% of patients over 50. In 2005 Wills Eye Hospital published the largest demographic data on older keratoconics available in the literature. A total of 279 patients were identified between the ages of 50 to 93 and this accounted for 40% of all keratoconics seen in Wills Eye Hospital the space of 1 year [10].

This study looked at the demographic data of the older keratoconics using optometric services as part of their keratoconus management in 5 NHS hospitals in Wales, United Kingdom. Collected data adds weight to the evidence that keratoconus is more common in males [1,11,12] and the possibility that they are identified earlier than females, although this difference has not reached statistical significance. The Dundee University Scottish Keratoconus Study (DUSKS) and data from New Zealand (NZ) study found a similar trend- an earlier age at diagnosis for male patients, with NZ data reaching statistical significance [12–14]. Earlier age at

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