

Epidemiological profile of patients waiting for penetrating keratoplasty in state of Pernambuco - Brazil

Perfil epidemiológico de pacientes na fila de transplante de córnea no estado de Pernambuco - Brasil

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ABSTRACT

Purpose: To describe the epidemiological profile of patients waiting for penetrating keratoplasty in state of Pernambuco, Brazil. **Methods:** Transversal and retrospective study, with 871 patients, in the period of 06/01/2011 a 05/31/2012, were registered on the waiting list for corneal transplantation in the Central of Notification, Captation and Distribution of Organs (CNCDO) of Pernambuco. Registration forms of cornea receiving were used, adapted to the purposes of this research. **Results:** In relation to frequency, it was obtained 54% female, 35% aged 61 to 80 years; 60% transplanted; 52% from the metropolitan area of Recife; 57% that waited 1 to 6 months the transplant; 82% with optical indication for transplant, 5% with priority on the waiting list (48% of those with ocular perforation) and; 37% whose transplant center was the Fundação Altino Ventura (FAV). The main indications for corneal transplantation were leukoma (33%), keratoconus (22%) e bullous keratopathy (18%). **Conclusion:** It was found that most patients were aged 61 to 80 years; was from the metropolitan area of Recife; was submitted to corneal transplantation; waited for one to six months to do the transplantation; had the diagnosis leukoma, followed by keratoconus and bullous keratopathy; was indicated to transplantation optical and had the transplant center to FAV.

Keywords: Health profile; Corneal diseases; Corneal transplantation/epidemiology

RESUMO

Objetivo: Descrever o perfil epidemiológico de pacientes na fila de transplante de córnea no Estado de Pernambuco, Brasil. **Métodos:** Estudo transversal e retrospectivo realizado no período 01/06/2011 a 31/05/2012, com 871 pacientes cadastrados na fila de espera para transplante de córnea na Central de Notificação, Captação e Distribuição de Órgãos de Pernambuco (CNCDO/PE). Os dados foram coletados por meio de protocolos baseados nas fichas de cadastro de receptor de córnea. **Resultados:** Em relação à frequência, obteve-se 54% do gênero feminino, 35% na faixa etária de 61 a 80 anos; 60% transplantados; 52% provenientes da região Metropolitana do Recife; 57% que aguardaram 1 a 6 meses o transplante; 82% com indicação de transplante óptico; 5% com prioridade na fila de espera (destes 48% por perfuração ocular) e; 37% cujo centro transplantador era a Fundação Altino Ventura (FAV). As principais indicações para transplante de córnea foram leucoma (33%), ceratocone (22%) e ceratopatia bolhosa (18%). **Conclusão:** Verificou-se que a maioria dos pacientes encontra-se na faixa etária de 61 a 80 anos; era da Mesorregião Metropolitana de Recife; foi submetida ao transplante de córnea; aguardou de um a seis meses para realizar o transplante; teve como diagnóstico o leucoma, seguido por ceratocone e ceratopatia bolhosa; teve como indicação o transplante óptico e teve como centro transplantador a FAV.

Descritores: Perfil de saúde; Doenças da córnea; Transplante de córnea/epidemiologia

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The authors declare no conflicts of interest

Received for publication: 14/3/2013 - Accepted for publication: 23/10/2013

INTRODUCTION

Corneal diseases are the second leading cause of reversible blindness worldwide. They affect a young and active population, producing an important economic and social burden. Despite current efforts, there is still a lack of donor tissues and eye banks to provide corneas in adequate number and quality for transplantation⁽¹⁾.

Spain is a world reference in organ collection, and the Spanish National Transplant Organisation determines that all hospitals must have a Hospital Transplant Commission. Since the establishment of these commissions from 1989 to 2001, the number of organ donors increased from 14 to 32.5 per million inhabitants⁽²⁾.

The number of corneal transplants is growing each year in Brazil. In 2008, 13,341 transplants were performed, and by 2011 the number had increased to 14,696⁽³⁾. In the State of Pernambuco there were 1,215 patients awaiting corneal transplantation at the end of 2011, but only 661 transplants were performed that year⁽⁴⁾. However, the greatest obstacle to an increase in donations is the lack of informed donors⁽⁵⁾.

The indications for penetrating keratoplasty vary in different regions of Brazil. Keratoconus is the main indication in São Paulo⁽⁶⁾, while in Sergipe the most frequent indication is bullous keratopathy, and keratoconus is the third most common indication⁽⁷⁾.

The number of surgical organ and tissue transplants has been shown to be increasing in recent decades. Corneal transplantation is the most common because of its easier technique and the number of donated organs⁽⁶⁾.

The present study aimed to delineate the epidemiological profile of patients awaiting corneal transplantation in the State of Pernambuco, Brazil.

METHODS

This was a cross-sectional retrospective study that included 871 patients registered on the waiting list for keratoplasty in the Organ Notification, Collection, and Distribution Centre (CNCDO) of Pernambuco from June 1, 2011 to May 31, 2012.

Patients whose registration data were incomplete and those with diagnoses inconsistent with indications for transplantation according to Ordinance 2600 were excluded from the study.⁽⁸⁾

Data were collected between June and August 2012 from the electronic registration records of cornea recipients in CNCDO/PE, adapted to the study objectives.

Study variables included sex, age, origin, ophthalmic diagnosis, date of inclusion in CNCDO, date of transplantation, time on the waiting list until transplantation, status on the waiting list, transplantation centre, indication, and transplantation priority.

According to Ordinance 2600⁽⁸⁾, potential cornea recipients can be classified on the Single Technical Registry as active, semi-active and removed. In this study, however, recipients were classified according to their situation on the waiting list as semi-active, suspended, dropout, and transplanted, as it is essential to know the number of transplants performed and the number of subjects who chose not to undergo transplantation.

Data were analysed using descriptive statistics methods. Charts and tables were prepared using Microsoft Excel™ 2007 software.

Table 1

Origin of patients registered in the Organ Notification, Collection, and Distribution Centre

Region in Pernambuco State	N	%
São Francisco	59	7
Sertão	52	6
Agreste	147	17
Mata	78	9
Recife Metropolitan Area	455	52
Other States*	80	9
Total	871	100

*Other States: Alagoas, Paraíba, Bahia, Sergipe, Piauí, Ceará, Roraima, and Amapá

Table 2

Waiting time for patients registered in the Organ Notification, Collection, and Distribution Centre

Waiting Time	N	%
Up to 29 days	153	29
1-6 months	302	57
7-11 months	68	13
1-3 years	4	1
Total	527	100

Table 3

Diagnosis of patients registered in the Organ Notification, Collection, and Distribution Centre

Diagnosis	Quantidade	%
Bullous keratopathy	155	18
Leukoma	288	33
Fuchs dystrophy	69	8
Keratoconus	188	22
Other*	15	2
Other corneal dystrophies	70	8
Secondary or late failure	86	10
Total	871	100

Other: keratitis and degeneration

RESULTS

Of the 871 study subjects, 54% were female; 35% were aged 61-80 years; 52% came from the Recife Metropolitan Area (Table 1); 60% had undergone transplantation, followed by 33% whose status was semi-active; 57% waited 1-6 months until transplantation (Table 2); 33% had a diagnosis of leukoma, followed by 22% with keratoconus and 18% with bullous keratopathy (Table 3).

Regarding the indications for transplantation, 82% were optical and 18% were tectonic, of which only 5% had priority status on the waiting list: 48% due to ocular perforation and 39% due to primary graft failure requiring retransplantation (Table 4).

Table 4**Reasons for priority transplantation among patients registered in the Organ Notification, Collection, and Distribution Centre**

Reason for priority	N	%
Ocular perforation	21	48
Descemetocoele	4	9
Corneal ulcer unresponsive to treatment	2	5
Retransplantation after primary graft failure	17	39
Total	44	100

Table 5**Transplant centre of patients registered in the Organ Notification, Collection, and Distribution Centre**

Transplant centre	N	%
FAV	323	37
HOPE	99	11
IOR	89	10
OTHER*	203	23
CMOV	85	10
IMIP	72	8
Total	871	100

IMIP: Integral Medicine Institute Professor Fernando Figueira; CMOV: Eye Clinic of São Francisco Valley; IOR: Recife Eye Institute; HOPE: Pernambuco Eye Hospital; FAV: Altino Ventura Foundation.

*Other: SEOPE: Pernambuco Eye Service; COC: Caruaru Eye Clinic; HOSL: Santa Luzia Eye Hospital; CSSHM: Senator Hermínio de Moraes Health Centre; RHP: Portuguese Royal Hospital; HC: University Hospital

The main transplant centre in the state of Pernambuco was the Altino Ventura Foundation with 37% of transplants (Table 5).

DISCUSSION

Corneal transplantation is the most successful procedure among tissue transplants in humans. Its goal is restoration of corneal transparency⁽⁹⁾.

According to some authors⁽¹⁰⁾, the consistent progress in techniques, organ processing, assessment, and conservation of corneas have led to an increase in the number of corneal transplants performed in Brazil⁽¹¹⁾ and in the State of Pernambuco⁽³⁾ and to a significant improvement in postoperative outcomes.

Moreover, there is greater public awareness of current treatment prospects and improved education of health care professionals with regard to the importance of cornea donation⁽¹²⁾, which helps increase the number of procedures performed in the country. Our results show a slight predominance of females among transplant patients. Previous studies conducted in Brazilian reference centres for corneal transplantation also found a predominance of females⁽¹³⁻¹⁵⁾, while others found a predominance of males^(12,16,17). This variability depends on the region, the studied population, and the time when the study was conducted.

Most patients were aged 61-80 years, confirming the findings of a study conducted in the Eye Bank of Base Hospital in São José do Rio Preto⁽¹⁶⁾ and showing that the mean age of transplant patients tends to be high. This can be explained by the ageing of the population in Brazil, which in 2009 had a life expectancy of 73 years⁽¹⁸⁾, as well as the increased awareness of patients regarding the treatment and prevention of ocular disorders⁽¹⁶⁾.

According to Ordinance 2600⁽⁸⁾, potential cornea recipients can be classified on the Single Technical Registry as active (able and available for transplantation), semi-active (incomplete pre-transplant workup, suspended by the medical team, or without clinical conditions), and removed (treatment dropout, refusal of transplantation, systematic refusals, prolonged semi-activity, removed by staff, removed due to lack of clinical conditions, transferred to another state, transplanted in another state, and transplanted abroad).

A patient removed due to prolonged semi-activity is a potential transplant recipient who has had a semi-active status for 120 cumulative days. A patient removed due to systematic refusal is a potential transplant recipient who has accumulated five refusals by the medical team to tissue offers by CNCDO from different donors at different dates⁽⁸⁾.

In our study there was a significant predominance of transplanted patients, underscoring the increasing number of transplants performed in the State of Pernambuco. However, the number of transplants is still far from ideal, as a third of subjects still had a semi-active status. This shows that the number of transplants performed in Brazil and worldwide is still insufficient for the number of patients on waiting lists⁽¹⁰⁾. This reflects the Brazilian reality where, despite efforts, there is still an unfortunate lack of donated tissues and eye banks to provide corneas in adequate number and quality for transplantation⁽¹⁾.

According to the Brazilian Ministry of Health⁽¹⁹⁾, in the Brazilian public health system the transplant waiting list for each organ or tissue is unique, and transplants are made on a first-come basis considering urgency and technical and geographic criteria.

Waiting lists result from a mismatch between demand and supply, and treatment delays have an adverse impact on therapy, the chances of cure, the nature and extent of disabilities, and the bio-psycho-social well-being of patients, family members, and society as a whole⁽²⁰⁾.

Our results show that most patients wait at most six months before undergoing corneal transplantation. This finding is in contrast with a study conducted in the state of Pará on 1271 patients, of which more than half had to wait 1-3 years before undergoing penetrating keratoplasty⁽²¹⁾.

The results of our study corroborate data from the Brazilian Association of Organ Transplantation which show that the number of corneal transplants has been increasing every year in Brazil⁽³⁾.

This progressive increase in the number of penetrating keratoplasties is due to several factors, including population ageing; better organisation of eye banks; better selection of donated tissues; and advances in pharmacology, immunology and ocular microsurgery, thanks to which transplants can be done in situations previously considered inoperable^(11,22).

However, in most Brazilian transplant centres the waiting period is still long and quite sensitive to variations in organ supply and demand. To reduce delays, national and international policies are needed to encourage donation and to reduce fears and insecurities on the part of the families of potential donors⁽²³⁾.

In a study with 42 patients submitted to penetrating kerato-

plasty, most were unaware of the actual importance of a transplant, revealing the lack of communication between doctors and patients, which leads to poor understanding of the types of corneal disease. This situation impairs proper recovery, even though most patients were satisfied with the outcome of surgery, albeit without the desired optical correction⁽²⁴⁾.

The knowledge and understanding a patient has of corneal transplantation is as important as the surgical technique itself. The lack of information on corneal transplantation and little awareness about the severity of the disease can lead to false expectations and failure to adhere to postoperative care and follow-up visits, which may compromise the surgical outcome and cause frustration⁽¹³⁾.

Therefore, patients awaiting transplantation should receive effective information prior to surgical treatment regarding their eye condition, the proposed procedure, intra- and postoperative care and risks, and the prospects for visual rehabilitation through educational lectures given by health care professionals^(13,24).

The State of Pernambuco is located in the northeast of Brazil and is divided into the following regions: São Francisco, Sertão, Agreste, Mata, and the Recife Metropolitan Area⁽²⁵⁾. In our study, most patients came from the Recife Metropolitan Area, as this population has greater access to public health services for the diagnosis, treatment, and monitoring of eye conditions.

It is important to note that 10% of patients transplanted in Pernambuco came from other Brazilian states, demonstrating the inability of other states to meet their demand for corneal transplants, thus overloading the health care systems of nearby states.

The most frequent indications for corneal transplantation may vary depending on the moment a study was conducted, data collection sites, population age, and environmental and cultural factors, among others⁽¹¹⁾.

It is therefore crucial to determine the indications for transplantation in order to adequately manage patients and improve their quality of life.

In our study, the main indication for corneal transplantation in the State of Pernambuco was leukoma, followed by keratoconus and bullous keratopathy.

This finding is in contrast with several studies in other parts of Brazil, Latin America and Europe, where keratoconus is the primary indication for corneal transplantation^(6,26,27). This can be attributed to better adaptation to and quality of contact lenses for visual correction as well as the use of intrastromal rings⁽²⁸⁾, which decrease the number of keratoconus patients undergoing transplantation.

Importantly, in another study conducted in the state of Pernambuco from January 1998 to December 2002, ulcerative lesions were important causes of corneal transplantation⁽²⁸⁾. In our study we found no such lesions, showing that the treatment of corneal ulcers has improved. However, it is worth noting that treated ulcers may produce scarring leading to leukoma.

With regard to the types of transplantation, we found a significant prevalence of optic indications. The main transplant centre in the state of Pernambuco was the Altino Ventura Foundation, responsible for almost half of transplants. This Foundation is headquartered in Recife and has clinics in other locations (Jaboatão dos Guararapes, Paulista, Salgueiro, and Arcoverde); it has been providing free health care to the population of the state for 26 years, with emergency care, outpatient units, and surgical procedures.

The importance of corneal transplantation should be better publicised and clarified in order to raise awareness, inform, and motivate potential donors. With this, the visual recovery and quality of life of patients would not be limited by the lack of available tissues for transplantation⁽¹⁰⁾.

Moreover, due to the high number of patients awaiting penetrating keratoplasty on the waiting list of CNCDO in the State of Pernambuco, health care professionals should be trained and educational campaigns should be undertaken to raise awareness on the need and importance of organ donation.

CONCLUSION

Among patients registered in the CNCDO of Pernambuco, most were aged 61-80 years; came from the Recife Metropolitan Area; were submitted to corneal transplantation during the study period; waited 1-6 months until transplantation; had a diagnosis of leukoma, followed by keratoconus and bullous keratopathy; had an optical indication for transplantation; did not get priority status on the waiting list, and, when they did, it was due to ocular perforation, followed by primary graft failure requiring retransplantation.

We also found that the main transplant centre in the state of Pernambuco was the Altino Ventura Foundation and that, among transplanted patients, the waiting time for corneal transplantation was inappropriately long.

Acknowledgements

The author would like to thank Professor Ana Catarina Delgado de Souza, Ph.D., director of the Recife Eye Bank, for dedicating her time and expertise to this work and the staff of CNCDO/PE who contributed with the data collection for this study.

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