Journal of Nursing
Revista de Enfermagem
UFPE On Line
ISSN: 1981-8963

ORIGINAL ARTICLE

EVALUATION OF THE QUALITY OF LIFE OF CORNEAL TRANSPLANT PATIENTS

AVALIAÇÃO DA QUALIDADE DE VIDA DO TRANSPLANTADO DE CÓRNEA

EVALUACIÓN DE LA CALIDAD DE VIDA DEL TRASPLANTADO DE CÓRNEA

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ABSTRACT

Objective*:** to evaluate the quality of life of corneal transplant patients. ***Method: cross-sectional and retrospective study with quantitative approach carried out with corneal transplant patients registered in the Notification, Procurement and Distribution Center of Organs. The study included 35 patients. Data collection was carried out with a questionnaire and data were stored in the Epi-Info 7.0 *software*, and then analyzed, presented in tables and discussed with literature. ***Results***: the profile of respondents was dominated by young and single men. Keratoconus was the major cause of indication to transplantation. Among patients, 42.86% are satisfied with their sight and 74.29% found that sight improved after transplantation. ***Conclusion***: transplantation influenced the quality of life of patients. ***Descriptors:*** Corneal Transplantation; Quality of Life; Visual Acuity.

RESUMO

Objetivo*:** avaliar a qualidade de vida dos transplantados de córnea. ***Método: estudo transversal e retrospectivo, de abordagem quantitativa, com transplantados de córnea cadastrados na Central de Notificação, Captação e Distribuição de Órgãos, realizado com 35 transplantados. A coleta de dados foi efetivada com um questionário e os dados armazenados no *software* Epi-Info 7.0; em seguida, analisados, apresentados em tabelas e discutidos com a literatura. ***Resultados***: no perfil dos entrevistados, destacou-se maioria de jovens do sexo masculino e solteira, o ceratocone foi a maior causa de indicação do transplante, 42,86% estão satisfeitos com visão, 74,29% acharam que a visão melhorou depois do transplante. ***Conclusão***: o transplante influenciou a qualidade de vida dos transplantados. ***Descritores:*** Transplante de Córnea; Qualidade de Vida; Acuidade Visual.

RESUMEN

Objetivo*:** evaluar la calidad de vida de los trasplantados de córnea. ***Método: estudio transversal y retrospectivo, de enfoque cuantitativo, con trasplantados de córnea registrados en la Central de Notificación, Captación y Distribución de Órganos, realizado con 35 trasplantados. La recolección de datos fue efectuada con un cuestionario y los datos almacenados en el *software* Epi-Info 7.0; en seguida, analizados, presentados en tablas y discutidos con la literatura. ***Resultados***: en el perfil de los entrevistados, se destacaron la mayoría de jóvenes del sexo masculino y soltera, el queratocono fue la mayor causa de indicación del trasplante, 42,86% están satisfechos con la visión, 74,29% creen que la visión mejoró después del trasplante. ***Conclusión***: el trasplante influyó en la calidad de vida de los trasplantados. ***Descriptores:*** Trasplante de Córnea; Calidad de Vida; Agudeza Visual.

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INTRODUCTION

Quality of life is a multidimensional concept focused in different contexts, both in health and disease, and affects individuals in general aspects. Although there are several definitions, the main concept that must be mentioned is the one proposed by the World Health Organization that includes the individual's perception of their place in life, in the context of culture and values on which is inserted and in relation to goals, expectations, standards and concerns.[1,2]

The success of corneal transplants results in better quality of life by allowing patients to develop their daily activities with quality. Corneal transplantation or penetrating keratoplasty is a relatively simple procedure and the most successful among tissue transplants. It is made from the replacement of the abnormal tissue by healthy corneal tissue from a donor. The procedure is indicated for cases of loss of sight by opacification caused by traumatic or metabolic factors. The most prevalent causes are bullous keratopathy, leucoma and keratoconus.[3-6]

Corneal diseases cause blindness and may lead individuals to major economic and social loss, impairing their quality of life. Corneal transplantation is intended to recover the sight and can be classified as optical, whose goal is to improve visual acuity, or tectonic when it seeks only to restore the anatomy of the eyeball whit serious structural changes.[3,5,7]

There are numerous ways of assessing quality of life. Measurement instruments depend on the approach and objective of the study. Specific questionnaires such as the Medical Outcomes Study Questionaire 36-Item Short Form Health Survey (SF-36) and the WHOQOL are some examples. Visual Function Test 14 (VF-14) was developed in the United States in 1994 by Steinberg with the aim to evaluate the correlation between visual acuity and the quality of life in people with eye problems, from a functional point of view. It is based on 14 daily activities which may be affected due to eye problems.[8-12]

The relevance of the study is anchored in the premises that the cornea is a tissue whose risk of rejection is low when compared to other transplants, and it is a simple procedure intended to provide improved visual acuity. Furthermore, in the State of Sergipe, Brazil, corneal transplantation is one of the few performed, and has great relevance. It is notable also that the number of studies addressing the issue of corneal transplant and its association with the quality of life of patients are scarce. Thus, it is important to provide scientific knowledge to society on the changes that occur in the life of a transplant patient.

Upon this background, the question that guided the development of this study was: Quality of life is present in the physical and in the spiritual and social spheres. Was there any improvement in their quality of life of patients who have undergone corneal transplantation? Thus, this article aims to:

- Assess the quality of life of patients undergoing corneal transplantation.
- Describe the sociodemographic profile of patients undergoing corneal transplantation;
- Check the reason for the indication of transplant.
- Compare visual acuity before and after transplantation.
- Evaluate post-transplant functional activity.
- Assess the patient's satisfaction with the procedure and to measure retransplantation rates.

METHOD

The study had investigative character with quantitative, cross-sectional and retrospective approach, and descriptive analysis.

Inclusion criteria adopted were: patients undergoing corneal transplantation from January 2011 to May 2015, of both sexes, aged over 18 and under 50 years, living in Aracajú. Transplant patients with tectonic cornea and those who changed their address and/or could not be found were excluded from the study.

Data collection was conducted from May to September 2015 in two phases. The first consisted in surveying data in the medical records of transplant patients in the Notification, Procurement and Organ Distribution Center of Sergipe (CNCDO/SE). This was done after approval of the project by the Ethics Committee of the University Tiradentes, under CAAE: 45989515.4.0000.5371. Then, the second phase of collection included communication and visits to the transplant patients in their homes, by prior appointment by telephone. Respondents received detailed information about the research, specifically on the objective. They were assured the freedom to accept or decline the invitation, and in case of acceptance, they signed the Informed Consent (IC), following the provisions of Resolution 466 of 12 December 2012 of the National Health Council.

As instrument of collection, a questionnaire prepared by the researchers themselves (Appendix 01) was used. This was subdivided into 4 areas: socio-demographic data, data regarding the transplant, the VF-14 questionnaire and data on the perception of the transplant. Data were organized in tables in Microsoft EXCEL 2013 program and analyzed using Epi Info version 7.0 software. They are represented in graphs and tables in order to facilitate the understanding and interpretation of results. All statistical analyses were performed with confidence interval equal to or below 5%.

RESULTS

The study population consisted of 560 users who underwent corneal transplants in the state of Sergipe in the period from 2011 to May 2015. Of these, 90 met the transplant inclusion and exclusion criteria. Among these, 3.3% refused to participate in the survey, 57.7% could not be located, and 38.8% (n = 35) signed the IC and represent the final study sample.

Distribution of results of categories in absolute and relative frequency (%) is presented for the surveyed variables of patients that underwent corneal transplant.

The profile of respondents revealed a predominance of males (54.29%), adults aged bewteen 36 and 50 years (40%) followed by respondents aged between 18 and 25 years (37.13%), and singles (74.29%). Schooling with highest prevalence was complete high school (25.71%). Among participants, 54.29% had paid work and 71.43% had family income of up to two minimum wages (Table 1).

Table 1. Sociodemographic characteristics of cornea transplant recipients. Aracajú (SE), Brazil, 2015.

Characteristics	n	%
Gender		
Male	19	54.29
Female	16	45.71
Age		
18 to 25 years	13	37.13
26 to 35 years	8	22.87
36 to 50 year	14	40.00
Marital Status		
Married	7	20.00%
Divorced	2	5.71%
Single	26	74.29%
Schooling		
Primary Education I	1	2.86%
Primary Education II	7	20.00%
Complete highschool	9	25.71%
Incomplete highschool	5	14.29%
Postgraduate education	3	8.57%
Complete higher education	3	8.57%
Incomplete higher education	7	20.00%
Paid work		
Yes	19	54.29%
No	16	45.71%
Monthly household income		
Up to 2 minimum wages	25	71.43%
3 to 6 minimum wages	6	17.14%
7 to 10 minimum wages	4	11.43%

Regarding the main indications for penetrating keratoplasty, keratoconus ranks first with 51% of cases. The second cause was corneal dystrophies (17%) and the third, leucoma of any etiology (14%). Indications by keratopathy bullosa (6%), Fuchs' dystrophy (6%), corneal degeneration (3%) and corneal congenital anomalies (3%) were less frequently observed.

Illnesses that were cited by respondents include myopia astigmatism, cataracts, leucoma, corneal degeneration, glaucoma, farsightedness, opaque retina. These diseases can appear isolated or in combination with others.

When analyzing the eye after the transplant, higher frequency of the left cornea, with 45.71% of caes, was observed. Most respondents did not undergo

retransplantation (82.85%) and 77.14% showed no graft rejection (Table 2).

Table 2. Transplant patients according to eye surgery, retransplantation and corneal graft rejection. Aracajú (SE), Brazil, 2015.

Variables	N=35	%
Operated eye		
Left	16	45.71%
Right	11	31.43%
Both	8	22.86%
Retransplantation		
Not performed	29	82.85%
Two retransplants	1	2.86%
One retransplantat	5	14.29%
Rejection		
No	27	77.14%
Yes	8	22.86%

By analyzing the waiting time for transplantation, we obtained an average of six months, the minimum time of eight days and the maximum of 26 months. This fact can be attributed to the increasing number of transplants performed, with consequent decrease in the time waiting on the list.

As for the use of optical correction, both glasses and contact lenses, 80% of respondents reported to use optical correction.

Regarding the perception of pain before and after transplantation, it was found in this study that 62.86% patients reported no pain before transplantation and 74.29% reported no pain after the procedure.

Table 3 shows the perception of participants about their sight before and after transplantation. It is found that 42.86% were satisfied with the current sight, 77.14% preferred the post-transplant sight and 74.29% found that sight improved after the procedure.

Table 3. Perception of participants on their sight before and after transplantation. Aracajú (SE), Brazil, 2015.

Variables	N=35	%
Are you happy with your sight?		
No	7	20.00%
Yes	15	42.86%
A little	13	37.14%
Do you prefer the sight you had before or the sight after the transplant?		
Before	8	22.86%
After	27	77.14%
Do you think your life has improved after the transplant?		
No	9	25.71%
Yes	26	74.29%

The adapted form of the visual function test (VF-14) made it possible to evaluate the degree of difficulty to carry out activities that depend on sight. This test showed that 46.45% participants did not have difficulties in carrying out activities, but 9.33% experienced severe difficulties in performing the various tasks cited.

The distribution of degree of difficulty to perform activities is shown in table 4 below.

Table 4. Distribution of patients according to the degree of difficulty. Aracajú (SE), Brazil, 2015.

Activity	Unable to perform	Intense difficulty	Moderate difficulty	Minimum difficulty	No difficulty	Not applicable	Total
Reading the newspaper	6	6	8	2	13	0	35
Recognizing people	4	3	2	3	23	0	35
Seeing steps	4	3	3	9	16	0	35
Traffic lights	5	6	1	12	11	0	35
Handicraft	7	0	2	9	17	0	35
Writing	4	2	4	4	20	1	35
Playing	6	0	5	4	20	0	35
Playing sports	4	3	2	6	19	1	35
Cooking	4	3	2	6	18	2	35
Watching TV	3	7	3	5	17	0	35
Driving during the morning	4	0	0	3	10	18	35
Driving during the night	5	2	5	2	3	18	35
Small print	9	5	9	8	4	0	35
Large Print	4	2	3	8	18	0	35

DISCUSSION

In a study on corneal transplants in Sergipe, the profile of receptients included the predominance of males, as in the present research, and a majority of patients in the age group of 59 years, followed by adults, youth and children. Patients over the age of 50 years were not included in the present study. The variables marital status, education, paid work and household income showed no significant difference regarding quality of life.[13]

It was found in the present study that the main indication for corneal transplant was keratoconus, followed by corneal dystrophy. A study conducted at the São Geraldo Hospital of the Federal University of Minas Gerais in 2010 found different results. They report that ulcerative lesion was the most frequent cause while other dystrophies were less frequent.[14]

Keratoconus is among the most indicated cases for keratoplasty. The disease affects individuals mainly from twenty to thirty years of age, hindering their sight due to deformity of the cornea. The disease can progress to astigmatism, which can be corrected with the use of glasses or contact lenses. It can also evolve to a more critical situation such as thinning and advanced protrusion, which cannot be corrected with optical features. Patients with these signs and symptoms should be submitted to transplantation.[5] Therefore, as keratoconus is a disease that affects younger people, it is understandable that this disease was the main indication in this study, since 60% of respondents are in the age range of 18 to 35 years. Likewise, bullous keratopathy was with one of the causes of this study for which there is little indication, as the age limit is 50 years.

According to a study, bullous keratopathy is a complication caused by cataract surgery, especially in phacoemulsification, and increased intraocular implants. The transplant due to bullous keratopathy is done on patients over 60 years when the cataract is the main cause.[4] Thus, attention is drawn to the fact that the patient who underwent two retransplants presented pellucid marginal degeneration, an unusual disease. The pellucid marginal degeneration is a variant of keratoconus, a rare corneal ectasia, noninflammatory, usually bilateral, which affects men and women between 20 and 40 years.[15]

Several factors can lead to rejection of corneal transplant. Among these are: donor age, preservation time and time between death and enucleation. The evaluation of rejection is made through cellular immune reaction process prior to surgery.[16]

The research conducted in the medical records of corneal donors and recipients in Sergipe in the years 2003-2008 showed that recipients with corneas captured by nurses had lower rejection rate when compared with those captured by another professionals.[14]

Whereas rejection of corneal graft happens in the postoperative period, the influence of this rejection is obviously associated with post-transplant care. Thus, the support from the nurses in providing guidelines to patients is necessary. A qualified nursing care, from capture of the cornea and post-surgery, can contribute to avoid rejections.[17]

Thus, nurses' contribution to promoting post-operative guidelines is fundamental, as care is the essence of nursing. Furthermore, it is worth emphasizing the need to direct a closer look at clients who rejected corneas, as many are weakened by the situation they are

experienced, as they expected a change in life.

Therefore, holistic nursing care could lead to better outcomes because nurses should be alert to the unique characteristics of each patient, respecting their values and feelings.[18]

In Brazil, 13,036 corneal transplants were performed in 2014, corresponding to an increase of 44.02% in the same period of 2007. The waiting list for corneal transplantation has decreased throughout Brazil. There was a reduction of 12,815 recipients from 2008 to 2014.[19]

Corneal transplantation is the most effective method for visual recovery and to relief symptoms such as pain, photophobia, and epiphora. A study on bullous keratopathy shows that the cause of the pain is associated with stromal edema and disruption of epithelial and subepithelial bubbles which irritates the corneal nerve endings, producing pain and discomfort on the ocular surface.[20]

It is worth mentioning the high rate of absence of pain after transplantation (74.29%) found in this study. This demonstrates that transplantation is imminently related to the reduction and/or absence of pain.

The analysis of distribution according to the degree of difficulty showed a positive relationship to the answer "no difficulty" in all activities. This finding may be explained by an improvement in all aspects of their functional ability to perform more effectively their daily activities.

The adapted VF14 questionnaire proved to be valid to evaluate the quality of life of patients after transplantation. This indicated that performing basic activities promotes an increase in the scores, highlighting the role of performing basic activities of daily life.

The changes in the living process of a patient with corneal disease cause successive changes in their daily routine. They can affect many further dimensions of social life. When patients undergo treatment for penetrating keratoplasty, they begin to overcome the limitations of the discomforts caused by transplantation and readjust their activities as much as possible.

CONCLUSION

The study addressed the quality of life of corneal transplant patients based on the use of a standardized collection instrument by the Brazilian Society of Ophthalmology, the VF14. This instrument allowed a better understanding of the quality of life of patients. It also caused a reflection on that the increasing number of transplants performed in Sergipe led to a reduction in the waiting list.

This paper described the sociodemographic profile of patients undergoing corneal transplantation. Male patients, aged between 36 and 50 years, single, with secondary education, with paid work, and with family income up to two minimum wages, were majority in the study. The main reason for indication of the transplant was keratoconus and retransplantation was uncommon. Most patients showed to be satisfied with the current sight, prefer the post-transplant sight, report that their sight improved after the procedure and say not to have difficulties in performing activities.

It was found that transplant patients feel satisfied with the transplant. The vast majority has a high degree of satisfaction because they are experiencing a new daily routine. Transplantation, therefore, promotes a better quality of life.

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Submission: 2016/04/05
Accepted: 2017/01/09
Publishing: 2017/02/01

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