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Ocupational performance and quality of life: interrelationships in daily life of visual impaired individuals

Desempenho ocupacional e qualidade de vida: inter-relações no cotidiano de pessoas com deficiência visual

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ABSTRACT

Objective: *Identify levels of self-perception of occupational performance and quality of life of individuals with visual impairment and subsequent analysis of the interrelationship between the indices found.* ***Methods****: Descriptive cross-sectional survey with people with visual disabilities enrolled in visual rehabilitation program. COPM was applied to measure the self-perception of occupational performance, the SF-36 for quality of life measurement and a socio-demographic questionnaire to describe personal characteristics.* ***Results.*** *Twenty-three subjects were included in the sample: 74% with low vision, 52.2% were female and mean age of 46.7 years. The self-perception of performance and emotional aspects domains of participants with low vision were better than those with blindness. The greater the time of visual impairment, worse was the self-perception of pain. The vitality domain showed statistical significant relationship with the domains general health, performance and satisfaction as well as the mental health domain were related to general health, pain, performance and vitality.* ***Conclusion:*** *The best were the mental health index, the better were the evaluations of physical, functional and social areas, a fact that indicates the importance of considering mental health in visual rehabilitation programs. The COPM and the SF-36 address the issue of functionality in different ways and their results are not compatible.*

Keywords: *Visually impaired persons; Task performance and analysis, Occupational therapy; Quality of life*

RESUMO

Objetivo: Identificar níveis de autopercepção de desempenho ocupacional e qualidade de vida de indivíduos com deficiência visual e posterior análise de inter-relação entre os índices encontrados. **Métodos:** Estudo descritivo de corte transversal junto a pessoas com deficiência visual inscritas em programa de reabilitação visual. Foram utilizados os questionários COPM para mensuração da autopercepção de desempenho ocupacional, SF-36 para mensuração de níveis de qualidade de vida e questionário de investigação sociodemográfico e perfil dos sujeitos. **Resultados:** Vinte três sujeitos compuseram a amostra, sendo 74% com baixa visão, 52,2% do gênero feminino e média de idade de 46,7 anos. A autopercepção de desempenho e aspectos emocionais dos participantes com baixa visão foram melhores do que os com cegueira. Quanto maior era o tempo de deficiência visual, pior era a avaliação da dor. O domínio vitalidade apresentou relação estatisticamente significativa com os domínios estado geral de saúde, desempenho e satisfação, assim como o domínio saúde mental apresentou relação com estado geral de saúde, dor, desempenho e vitalidade. **Conclusão:** Quanto melhores foram os índices de saúde mental, melhores foram as avaliações dos domínios físicos, funcionais e sociais, fato que indica a importância de considerar a saúde mental em programas de reabilitação. A COPM e a SF-36 abordam a questão da funcionalidade de maneiras distintas e seus resultados não são compatíveis.

Descritores: Pessoas com deficiência visual; Análise e desempenho de tarefas; Terapia ocupacional; Qualidade de vida

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Introduction

Understand the daily life of visual impaired individuals, who are characterized by a singularity that often implies in differences in early and late human development, considering the psychomotor and socio-cultural spheres in comparison to those who are not[1], optimizes the quality of therapeutic projects and public health actions.

This paper is about adults with visual impairment who attend a university visual rehabilitation center in Campinas-Brazil, all diagnosed with low vision or blindness and their perceptions on their occupational performance and quality of life.

The World Health Organization (WHO)[2] estimates that there are 285 million visual impaired individuals in the world and, out of them, 39 million are blind and 246 million have low vision. Also according to WHO[3], the main causes of visual impairment in the world are catarata (47.9%), glaucoma (12.3%), age-related macular degeneration (8.7%), corneal opacity (5.1%), diabetic retinopathy (4.8%), childhood blindness (3.9%), trachoma (3.6%), and onchocerciasis (0.8%). Therefore, considering such alarming data, the study of visual disabilities and their socio-historical context contribute to the development of knowledge on skills, different forms of social interactions and ways to intervene with these individuals, their families and communities[3].

Like Winnicott[4] says, our equipment for life is a body and a personality full of singularities that gives us essential differences. The advantageous or disadvantageous character about these differences is determined according to the way it interacts with the environment. If a particular feature helps individuals to efficiently cope with the demands of their environment, it is advantageous. However, if it weakens them before any demand, it becomes disadvantageous. In addition, in several of the individuals' relationship to their environment, some of their qualities are not advantageous or disadvantageous. The meaning attributed to a feature will depend on three factors: the individual or actor, the audience or the judge and the circumstances under which the trial takes place[4].

Must be considered that each person is, before any reduction to a stigmatizing feature, someone with a life story full of meaning, experiences and wisdom and this should be considered in any intervention context as in most daily life situations.

The visual impaired individuals daily activities study could be developed with the support of the Canadian Model of Occupational Performance, that is characterized by client-centered practice and understands the individual as being composed of physical, affective and cognitive components all interconnected with the essence of "being", which is the spiritual element, besides considering that the environment consists of physical, social, cultural and institutional elements. This model classifies human occupation in three categories of activities, each containing some subcategories, as follows: self-care (personal care, functional mobility and functioning in the community), productivity (handling household chores and playing/school) and leisure (calm recreation and active recreation)[5].

The aims of a visual rehabilitation work could be to understand and deal with fears and anxieties, orientation and mobility, time and space orientation techniques, teaching new skills and stimulating existing skills, practical and daily life activities, social interaction and adaptation to the environment, thus working with all aspects that will help these individuals feel confident and able to return to an active life in society[5,6].

Previously knowing the difficulties in performing daily activities that compromise the functionality of individuals with visual impairment who seek a visual rehabilitation service, optimizes treatment time and motivates the individuals and their families[7]. With impaired eyesight, individuals are faced with problems such as social interaction, finding job and performing daily activities with independence and autonomy, resulting in a process of possible loss of self-esteem and self-worth[8]. In addition to the possibility of drop in the level of performance and emotional fragility, these individuals have their occupational performance compromised, consequently decreasing their quality of life.

The study of quality of life is an attempt to understand the human subjectivity that permeates the physical, mental and social well-being. However, to evaluate and measure quality of life requires a holistic understanding of the human being and society and is a quite complex action.

The World Health Organization (WHO[9]defines quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" and its multidimensionality justifies the various ways it impacts life in society[10].

This research is intended to provide data that characterizes the daily routine of this population using internationally validated instruments, contributing to the knowledge development about self-perception visually impairment individuals about their own limitations and on environmental constraints that impact their autonomy and functionality in society. The main purpose of this study is to identify levels of self-perception of occupational performance and quality of life of individuals with visual impairment and identify the relationship among the rates found for each investigated aspect.

Methods

This is a descriptive and cross-sectional survey, in which the self-perception of occupational performance was measured through the application of the Canadian Occupational Performance Measure (COPM) and the self-perception of quality of life through the application of SF-36 with visual impaired individuals enrolled in a visual rehabilitation program of the Center for Studies and Research in Rehabilitation*"Prof. Dr. Gabriel Porto"- CEPRE*, Faculty of Medical Sciences (FCM)-University of Campinas/Unicamp.

Participants

The research sample consists of 23 subjects who have been diagnosed with visual impairment (low vision or blindness) for over a year, aged 18 and older, ever participated in a visual rehabilitation program before data collection, who was accessing for the first time the visual rehabilitation program at Center for Studies and Research in Rehabilitation *"Prof. Dr. Gabriel Porto"- CEPRE*.

Instruments

Three instruments were used: a questionnaire to investigate the socio-demographic profile of the participants, developed by the researchers; The Canadian Occupational Performance Measure – COPM; and the Medical Outcomes Study 36 - Item Short Form Health Survey - SF-36.

The first publication of the COPM took place in 1990 and since that it has been improved and translated into several languages, being used in over 35 countries. In Brazil, the COPM was translated in 2009 by Magalhães L C, Maga-

lhães L V and Cardoso A A, all linked to the Federal University of Minas Gerais[11].

This scale is a semi-structured questionnaire that measures the self-perception of clients in relation to their occupational performance and is grounded in Canadian Model of Occupational Performance concepts. This model suggests that occupational performance is a result of the relationships between the person, environment and occupation. The occupation can be classified into three categories - self-care, productivity and leisure - and other three sub-categories for each category: in the Self-care category, the subcategories are Personal Care, Functional Mobility, and Functioning in the Community; in the Productivity category, the subcategories are paid work or not, management of house keeping and school and play; and in the leisure category,the subcategories are calm recreation, active recreation and socialization[11].

The SF-36 questionnaire is a general and multidimensional instrument of quality of life and its concepts are not specific to an age range, disease or treatment group. It consists of thirty-five questions covering eight domains: functioning capacity, physical aspects, pain, general health, vitality, social aspects, emotional aspects and mental health – in addition to a question that compares the self- perceived health of today and a year ago[12].

Data collection

The data collection interviews were integrated into the evaluation process of new users at CEPRE/Unicamp and this was the first contact with the service. Initially, anamnesis was carried out for socio-demographic profile collect data, then COPM was applied and, finally, the SF-36 questionnaire, in the period from august 2011 to march 2012.

Data analysis

The data were first analyzed as to their normality and homogeneity by the Shapiro-Wilk and Levene tests. To verify if the gender or professional practice would influence the dependent variables with normal distribution (functional capacity scores, mental health, vitality, social functioning, general health, physical, performance and satisfaction) was applied *t* Student Test and to verify if the gender and professional practice influence the other variables (pain, social and physical aspects) the Mann-Whitney test was conducted. To verify if the educational level and age (independent variables) influenced all dependent variables (functional capacity scores, mental health, vitality, social functioning, general health, physical, performance, satisfaction, and pain) were applied ANOVA one-way and, if necessary, post-hoc Tukey. To evaluate the influence of categorical variables on each other (if the visually impaired and the education levels influence the professional practice and if visual impairment impacts is related to education levels) Q-square tests were applied. Finally, to assess whether there is a correlation between all variables, Pearson's correlation and Spearman tests were applied depending on the variable normalitv- in which the higher the value of the correlation coefficient (r) of both positive (> 0) and negative (< 0) was, the stronger was the association between the variables. All tests were conducted in Statistica 7.0 software and the variables were considered statistically significant when $p < 0.05$.

Results

The socio-demographic characteristics of the non-probabilistic sample was: average age of 46.7 years, out of which 52.2% were females, most with low vision (74.0%) and with acquired visual impairment (73.8%). The age of onset of visual impairment was between 31 and 51 years of age (the average age was 36.5 years). The main causes of visual impairment among respondents were macular chorioretinitis due to toxoplasmosis (17.4%), followed by cataract (13.0%), diabetic retinopathy (13.0%) and Stargardt Disease (8.7%). Most respondents completed high school (52.2%) and only 13.0% of the sample was involved in professional activity, all of them with low vision. The activities that were most frequently mentioned by participants as difficult to perform, in accordance with the Canadian Model of occupational performance, a report of the self care category, in functioning in community subcategory (table 1).

Table 1

Activities mentioned by the survey participants as difficult to perform and classified under the self-care category and its subcategories in accordance to COPM

n = 23*

Self-care activities	*f*	%
Personal Care		
Choosing clothes	6	7.7
Putting toothpaste on the toothbrush	2	2.5
Applying adhesive cream to the denture	1	1.3
Being organized with the medication	1	1.3
Taking showers	1	1.3
Putting water in the glass	1	1.3
Functional Mobility		
Finding objects	1	1.3
Going down steps	1	1.3
Functioning in Community		
Taking the bus	12	15.3
Walking alone on the street	8	10.2
Going across the street	2	2.5
Analysing merchandise prices in stores	1	1.3
Reading signs on the street	1	1.3
Using an analog and digital watch	1	1.3
Using landline and cell phone	1	1.3
Using the bank	1	1.3

(*) Multiple responses

Afterwards, in second place, was the productivity category, in the management of housekeeping subcategory (table 2).

Table 2

Activities mentioned by the survey participants as difficult to perform and classified under the productivity category and its subcategories in accordance to COPM

n = 23*

Productivity	*f*	%
Handling household chores		
Cooking	8	10.2
Sweeping the house	6	7.7
Washing and ironing clothes	4	5.1
Doing the dishes	2	2.5
Serving yourself	2	2.5
Performing minor repairs at home	1	1.3
Making your bed	1	1.3
Playing/ School		
Following the teacher's talk	1	1.3

(*) Multiple responses

Overall, 28 activities considered difficult to perform were cited by the participants, totalling 76 multiple responses. Out of these responses, 57.10% fell within the self-care category (table 1), 28.60% into the productivity category (table 2) and 14.30% in the Leisure category (table 3).

Table 3

Activities mentioned by the survey participants as difficult to perform and classified under the leisure category and its subcategories in accordance to COPM

n = 23*

Leisure	*f*	%
Calm recreation		
Reading	7	9
Writing	3	3.8
Watching TV	1	1.3
Active recreation		
Fishing	1	1.3

(*) Multiple responses

Regarding the levels of occupational performance, in the 1 to 10 scale proposed by Law et al.[11], a final average of 3.9 was found for performance and 3.8 for satisfaction.

The results of the SF-36 questionnaire application, on a scale of 0 to 100, showed that the participants had a good assessment of their functional capacity, obtaining a final average of 75.8, and considered physical aspects their worst quality of life feature, with the low final average of 23.9.

Some domains that make up the quality of life presented rates higher than 60 and therefore these are the domains in which respondents rated their best quality of life, as follows: vitality (69.1), mental health (64.8), general health (63.5) and social aspects (60.8), in addition to functional capacity (75.8) which was rated as their best feature.

From this on, it was possible to verify the level of association between the domains that compose the COPM and SF-36 (table 4) scales, making it possible to obtain very interesting results.

Table 4

Values of correlation coefficients (r) relating to the crossings of the results found with the application of COPM and SF-36

Domains	MEH	VIT	GEH	PYA	SCA	EMA	PAI	FUC	PER	SAT
MEH	1,000	0,784	0,514	NS	NS	NS	0,484	NS	0,429	NS
VIT		1,000	0,471	NS	NS	NS	NS	NS	0,557	0,503
GEH			1,000	0,445	NS	NS	NS	NS	NS	NS
PYA				1,000	NS	0,640	NS	NS	NS	NS
SCA					1,000	NS	NS	NS	NS	0,450
EMA						1,000	NS	NS	0,454	NS
PAI							1,000	NS	NS	NS
FUC								1,000	NS	NS
PER									1,000	0,487
SAT										1,000

NS = not significant
n = 23

The mental health (MEH) domain of the SF-36 scale stood out for having the largest number of statistically significant associations with other domains: general health (GEH), performance (PER), pain (PAI) and vitality (VIT).

Another domain that was highlighted due to association with others was vitality. It was statistically associated with performance, satisfaction (SAT) and general health.

The emotional aspects domain showed statistically significant associations with the physical aspects (PYA) domain of the SF-36 questionnaire and the performance (PER) domain of COPM.

Another case of a statistically significant association between domains was between the social aspects (SOA) of SF-36 and satisfaction assessed by COPM.

Discussion

Regarding the socio demographic data found in the research, similar results were found in another study conducted in 2011[13], also at CEPRE- FCM-UNICAMP. For example, the average age of this sample was 46.7 years old, while in this another study was 41 years, showing that maybe this is the approximated majority age that people with visual impairment search for an visual rehabilitation program. Another finding with similar values between the two studies is related to the frequency in the type of visual impairment. In this study, blindness represents 26% of the interviewed cases and low vision the remaining 74%, while in the study carried out in 2011, 34.8% of cases represented blindness and 65.2% represented low vision, corroborating with other studies datas that indicate that low vision is more prevalent in the general populationthanblindness[9,14].

According to diagnosis found as cause of visual impairment, toxoplasmosis chorioretinitis (17.4%) and diabetic retinopathy (4.3%) were highlighted as the most incidents preventable diseases.

Unfortunately, it worth pointing out that the toxoplasmosis infection is still common in the Brazilian population. The significant incidence of toxoplasmosis is a result of low socio-economic conditions still found in several regions in Brazil and it is even more impressive when it has congenital character an disassociated

with intellectual disability. Congenital toxoplasmosis and its consequences can be prevented through primary prevention, providing the necessary information to susceptible pregnant women, mainly information on the sources of infection and prevention[15].

Diabetic retinopathy is considered a preventable disease by WHO and in 2002 represented 4,8% (or 5 million people) of blindness cases in the world[16-18]. As the incidence of diabetes increases gradually over the years, there is a possibility that more people will suffer from eye complications and, if not properly controlled, it can result in permanent visual damage. Health promotion actions that address topics such as healthy eating can be effective in controlling the disease progression[17].

Regarding the results from the application of the COPM, some of the activities cited by respondents as difficult to achieve required levels of certain skills such as discrimination of colors, textures and shapes, spatial orientation and body schema.

'Taking urban buses' was the most frequently mentioned activity (twelve times), followed by 'walking alone on the street' (eight times). This shows that to the visually impaired individuals interviewed, it was very difficult to use public transport and that they felt unsafe to walk independently on the city's streets. A significant percentage of people with visual impairments tend to fall while walking at least once a month, requiring medical care, and the frequency of this event interferes in walking routine, reducing the confidence to walk unaccompanied[19]. The adjustment lack with the environment, tools and public transport hamper the independent performance of several activities mentioned by the participants.

Nowadays, studies has already described features or instruments that has potential to facilitate the mobility of these individuals, such as sound traffic lights, tactile floors, elimination of barriers on sidewalks, such as signposts, public telephones, trees, gardens and poorly positioned trash cans, in addition to communication media adapted to the use of Braille and audio devices, but all of these tools are not commonly used in Brazil. The environment in which individuals live has a significant impact on the experience and the extent of their disabilities. Inaccessible environments generate disabilities by creating barriers to participation and inclusion[20].

The difficulties in occupational performance mentioned by the respondents show that they could benefit from a visual rehabilitation program as most include activities that can be supported by suitable low-tech tools and skills development techniques that are present in a program of this type, tools used primarily by occupational therapy professionals as habilitation strategies or visual rehabilitation.

Visual rehabilitation aims to maximize the use of the residual vision of individuals, optimizing their autonomy and independence in the habilitation or rehabilitation in basic activities of daily life, in productive activities and also in leisure, providing security and confidence in the integrated use of their remaining senses[6,10,21].

Regarding rates of occupational performance, the low self-evaluation found for satisfaction in regard to performance can make these individuals lose their motivation to maintain an active attitude about their own lives or about the lives of people with whom they relate. In addition to impaired performance, another factor that may have contributed to the low rates of satisfaction is the process of stigma internalization, in other words, individuals recognize themselves as stigmatized, which reduces their self-esteem and self-efficacy, perception of disrepute, limited prospects for recovery and restriction of social networks[22].

Regarding the quality of life self-evaluation, the results stand in opposition to those found with the application of COPM regarding functionality/performance. This is because the results of COPM showed low levels of performance in daily life activities of the sample, while the highest final average found for the domains of quality of life assessed is relative to functional capacity.

Note that the concepts underlying each of the questionnaires differ. COPM considers and evaluates the functionality of respondents in activities that are culturally and contextually relevant to them. Moreover, in COPM it is suggested to respondents that they provide scores to the activities that they are struggling to accomplish at the moment, so the results found are not obtained by measuring data from the assessment of activities that are not a problem for them or that do not have meaning in their daily lives. SF-36,on the other hand, is a closed questionnaire that assesses pre-determined activities such as running, lifting heavy objects, playing ball, sweeping the house, climbing several flights of stairs, kneeling, bathing, dressing, walking several blocks, among others,in other words, activities that are not found to be relevant by this sample, thus making the results unreliable when considering the reality of these individuals.

Considering the most significant interrelations found between the assessed domains, we highlight the mental health of SF-36, as it presented the highest number of statistically significant relations with other domains: general health, pain, vitality and COPM's performance. These findings are consistent with another research[23] which concludes that visual ability is a multidimensional construct determined by visual acuity, physical ability cognition and mental states, like depression, explaining more than one-third of the variance in visual ability.

The Physical Aspects domain obtained the lowest average - 23.9 – among the respondents, a fact that is consistent with the type of disability experienced bythese individuals. The physical conditions self-evaluation of this sample was the factor that most contributed to the low final level of quality of life. Another study[24] that used the SF-36 scale to investigate the quality of life of elderly people with visual impairment, athletes and non-athletes, also found low rates for physical aspects - 51.6 - from sedentary people, however, high rates were obtained by respondents who used to practice sports - 93.1 - causing the authors to conclude that practicing sports optimizes thelevels of quality of life in these individuals.

About the application of COPM, it has shown to be an important strategy for professionals who want to get closer to the everyday reality of their clients. Through its application, it is possible to understand the daily life of individuals affected by visual impairment, enabling the analysis of the demands of each task that is important to the occupational performance of respondents.

Conclusion

The frequency of low vision and blindness found in this study corroborates with the prevalence of these disease in another important studies in the same area, which punctuate the existence of more individuals affected by low vision than blindness in the world. The main causes of visual impairment among the respondents are also consistent with the WHO data, especially with the alarming incidence of preventable cases of

diabetic retinopathy and chorioretinit is due to toxoplasmosis in the Brazilian territory.

The self-perception in regard to occupational performance was low for individuals with visual impairment, but individuals affected by low vision assessed their performance better than individuals affected by blindness.

The quality of life domain that was best rated was functional capacity and physical aspects was the worst. Only emotional aspects and physical aspects domains were rated below average.

When analyzing the association of the results from SF-36 with the results from COPM, we conclude that although most of the independent findings of both scales are reliable in regard to reality of the sample, the analysis of the data association related to the Functional Capacity domain of SF-36 and the Performance domain of COPM suggest essential differences in theoretical basis for the two scales regarding the respondents' functionality approach. Therefore, the combined use of these two scales is not suitable for analyzing the functionality of visually impaired individuals.

Regarding mental health levels and their interrelations with other assessed domains, it is possible to affirm that this aspect is associated with respondents emotional and functional issues, with the self-perception of General Health and also in how they perceived their occupational performance in carrying out activities they consider important in their lives.

This study reiterates the benefits that individuals affected by visual impairment may achieve from participating in rehabilitation programs that count on interdisciplinary teams with the aim of providing the highest possible level of autonomy and independence in their daily activities.

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