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RESEARCH ARTICLE

Caregiving Children with Visually Impairments: Occupational Balance and Quality of Life Perspective

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Abstract
Several studies have shown that caregivers of children (COC) with special needs have their occupational balance (OB) or quality of life (QOL) worsening. However, the OB and QOL of COC with visual impairment are not adequately investigated. Fifty-nine participants who were the primary COC who were diagnosed with either low vision (LV) or blindness completed the study. Occupational Balance Questionerrie Turkish version and the WHO Quality of Life Scale-Short Form Turkish version were applied. The correlation analysis was used to test the correlation between the OB and QOL scores. The Mann-Whitney U used for comparing OB and QOL scores between the COC with LV and blindness. There was a positive correlation between caregivers' OB and QOL (r=0.600; p>0.05). There was no statistically significant difference between OB and QOL of the two groups of caregivers (p>0.05). There are many issues that occupational therapists should support and investigate about this family. We think that the quality of life, balance of activity and efficient use of the time of COC with VI should be further investigated by occupational therapists.

Keywords
Occupational Balance, Quality of Life, Children With VI, Caregiver

INTRODUCTION

Visual impairment (VI) is caused by various diseases or degenerative conditions and leads to significant limitations in vision that cannot be corrected by conventional methods (Elgendy, Sik-Lanyi, & Kelemen, 2019). According to the World Health Organisation (WHO), 285 million people worldwide have VI due to both eye diseases and uncorrected refractive errors, while seven million children have VI. Ten million children have correctable refractive errors (bilateral visual acuity <6/18), and about 1.4 million children have blindness (WHO, 2022).

In childhood, the motor, cognitive and psychosocial development of children with LV can be affected (Rainey, Elsman, van Nispen, van Leeuwen, & van Rens, 2016). In addition, the visual function may affect children's daily living activities, academic skills, participation in leisure time, and socialization activities (Lupón, Armayones, & Cardona, 2018). These difficulties faced by children with LV affect the quality of life (QOL) not only of the child but also of all family members (Lupón, Armayones, & Cardona, 2018; Rainey et al., 2016).

Caregivers of children with special needs are faced with role changes that affect their

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personal lives, social interactions, expectations, plans, and work experiences. This role changes lead to many problems affecting caregivers' QOL and well-being (Kuo et al., 2011; Van Cleave, 2015). Lupón et al. stated that caregivers' quality of life is negatively affected, and low quality of life is associated with psychosocial well-being (Lupón et al., 2018).

The term occupational balance (OB), which is frequently used by occupational therapists, has been defined as the subjective experience of having the right number of occupations and the correct variation between occupations in the occupational pattern (Güney Yılmaz, Avcı, & Akı, 2022; Wagman, Håkansson, & Björklund, 2012). Several studies have shown that COC with special needs have their OBs worsening. In addition, the time allocated by these individuals for themselves has decreased depending on the burden of care (Engelen, 2017; McGuire, Crowe, Law, VanLeit, & Health, 2004). A consensus has emerged that engaging in various occupations in a sufficient and satisfying pattern in line with life roles improves health and well-being and reduces stress (Anlaby, Jarus, Backman, & Zumbo, 2010). A good OB leads to a healthy life and supports well-being (Bejerholm, 2010). Wagman and Hakanson stated that the deterioration or decrease in OB might be related to individuals' QOL (Wagman & Håkansson, 2014a).

Factors such as QOL, caregiver burden, and parental stress of COC with visual impairment have been examined in the literature (Kantipuly et al., 2019; Kuriakose, Khan, Almeida, & Braich, 2017; Lupón et al., 2018). However, the OB and QOL of COC with visual impairment are not adequately investigated in the literature. Also, it has not been investigated how caregiving for children with LV and VI affects QOL or OB. This study aims to examine the relationship between the OB and QOL of COC with VI and to compare the OB and QOL between COC with LV and blindness.

MATERIALS AND METHODS

Participants

The study was completed with 59 participants who were the primary COC under the age of 18 who were diagnosed with either LV or blindness. Illiterate persons and those who did not voluntarily accept participation in the study were excluded from the study.

The 59 parents in this study consisted of 45 mothers and 14 fathers. The mean parental age was 34.3 (± 5.85) years, and the mean age of the children was 5.4 (±3.32) years. Thirty-four of the children had LV, and 25 had a diagnosis of blindness. While 43 of the caregivers were not working at any job, 16 caregivers were working while continuing to caregiving. While only 14 caregivers received support in caring for children, 45 participants undertook caregiving alone. Parent and child characteristics are summarised in Table 1.

Procedure

The sampling of the study was formed by the COC with visual impairment who were previously followed up in the Hacettepe University Faculty of Health Sciences Occupational Therapy Department. The invitations containing the research content were sent online to the caregivers. The questionnaire forms and family consent of the families who accepted to participate were created with Google Forms and sent to the families via e-messages such as e-mail and other online messaging services. Demographic information forms, Occupational Balance Questionerrie Turkish version (OBQ11-T), and World Health Organization Quality of Life Scale-Short Form Turkish version (WHOQOL-BREF TR) were applied to the individuals participating in the study. Evaluations were conducted with individuals through social networks and phone calls due to the pandemic. The study was approved by the local institutional ethical board (Hacettepe University Non-Interventional Clinical Research Ethics Committee, (registration number GO 20/1093).

Instruments: Participant characteristics

Demographic information form:

A form containing the age, gender, VI, and demographic information of the caregivers such as age, gender, educational status, employment status, and relationship level was applied. In addition, it was asked whether they were giving care to another individual and whether they received support from another person in caregiving.

Instruments: Quality of Life

WHOQOL-BREF TR:

The Turkish version of WHOQOL-BREF TR consists of 27 items, while the original version of the scale consists of 26 items (Eser et al., 1999). The scale includes, general health status (GH); Physical Health (PH); Mental Health (MH), Social relations (SE); Environmental Health (EH) subtests. Each item is scored on a 5-point Likert scale. The scale also includes two items consisting of QOL and general health items. WHOQOL BREF TR is calculated over 20 points. The raw scores are converted to percentages. A high score on the scale indicates a high QOL (Eser et al., 1999; Whoqol Group.,1998).

Table 1. Participant characteristics of children (N=59).

	M (SD)	Range
Age of Children (years)	5.4±3.32	0-15
Caregivers' Age (years)	34.3± 5.85	26-56
	Frequency (%)	
	Low Vision (n=34)	**Blind (N=25)**
Gender: Children		
Male	14 (%41.2)	18 (%72)
Female	20 (%58.8)	7 (%28)
Caregiver gender		
Female	31(%91.2)	14 (%56)
Male	3(8.8)	11 (%44)
Kinship with the child		
Mother	31(%91.2)	14 (%56)
Father	3(8.8)	11 (%44)
Caregiver education level		
Primary school	5 (%14.1)	9 (%36)
Middle School	7 (%20.6)	3 (%12)
High school	11 (%32.4)	8 (%32)
University	11 (%32.4)	5 (%20)
Caregiver work status		
Working	7 (%20.6)	9 (%36)
Not working	27 (%79.4)	16 (%64)
Secondary diagnoses coexisting with VI (such as CP, autism, ADHD)		
Yes	19 (%55.9)	8 (%32)
No	15 (%44.1)	17 (%68)
Support during caregiving		
Yes	4 (%11.8)	10(%40)
No	30 (%88.2)	15 (%60)
Does the child attend school?		
Yes	11 (%32.4)	15 (%60)
No	23 (%67.6)	10 (%40)

M: mean; SD: standard deviation. VI: Visual Impairments; CP: Cerebral Palsy; ADHD: Attention-deficit/hyperactivity disorder

Instruments: Occupational Balance

OBQ11-T:

It is a scale that measures the OB of an individual. The purpose of the scale is to measure satisfaction according to the amount and variety of daily occupations of the individual and to describe the OB according to the results obtained (Wagman & Håkansson, 2014b). A Turkish validity and reliability study was conducted for the 11-item version of the test with 0.922 test and retest coefficient and 0.785 Cronbach alpha (Günal et al., 2020). Each item in the scale is scored on a 4-point Likert scale (0-3) between "absolutely disagree" and "absolutely agree". The total score ranges from 0 to 33 by summing up item scores, with higher

Data analyses

All analyses were performed using the Statistical Package for the Social Sciences (SPSS) software version 23. Descriptive statistics, including frequency, percentage, median, and minimum/maximum values, mean, and standard deviation were used. The normality of the distribution was analyzed by the Kolmogorov-Smirnov test. Since the data were non-normally distributed, the Spearman correlation analysis was utilized to test the correlation between the OB and the COC with LV and blindness. Although there is no cut-off value for OBQ, the higher score obtained from the test increases the OB level (Günal et al., 2019). Therefore, the raw score was used to interpret the OB scores of the families.

RESULTS

OB of Caregivers

The caregivers' mean score for the OBQ11-T was 12.37 ± 6.70. While this average was 13.02 ±6.9 for COC with LV, it was 11.48±6.43 for COC with blindness. Statistically significant difference comparing OB and the QOL scores between QOL scores. The Mann-Whitney U used for between the OB of the two groups of caregivers couldn't found (p>0.05) (Table 2).

QOL of Caregivers

While the median percentage value of the caregivers' WHOQOL total percentage score was 50.00, GH was 50.00; PH was 53.57; MH was 54.16; SH was 50.00; EH was 46.87 (Table 3). While statistically significant differences in GH scores between COC with LV and blindness (p <0.05); there were no significant differences between PH, MH, SH, EH, and T scores (p> 0.05) (Table 2).

Table 2. Difference between the OB and QOL scores of caregivers of children with low vision and children with blindness

	Low Vision (N=34)		**Blind (N=25)**		**Mean difference (MWU)**	
	Mean/SD	***Median*** ***Min-Max***	***Mean/SD***	***Median*** ***Min-Max***	***Z***	***p***
OBQ11-T:	13.02±6. 9		11.48±6.43		-.845	0.398
WHOQOL-GH (%)		50 25-100		50 0-87.50	-2.033	0.042*
WHOQOL-PH (%)		60.71 17.86-100		50 21.43-92.86	-1.39	0.164
WHOQOL-MH (%)		56.25 16.67-95.83		54.16 8.33-87.50	-.555	0.579
WHOQOL-SH (%)		50 0-100		50 0-91.67	-.857	0.391
WHOQOL-EH (%)		48.43 9.38-93.75		46.87 0-90.63	-1.316	0.188
WHOQOL-T (%)		56.01 20.37-93.52		48.14 11.11-87.04	-1.029	0.303

p<0.05*; p<0.001**; Max: Maximum; Min: Minimum; MWU: Mann Whitney U Test; OBQ11-T: Occupational Balance Questionerrie; SD=Standard Deviation; WHOQOL: World Health Organization Quality of Life Scale Short Form. GH: General Health. PH: Physical Health. MH: Mental Health. SH: Social Health. EH: Environmental Health. T: Total Score

The Relationship Between QOL and OB of Caregivers

Positive correlation between caregivers' OB and QOL was found. There were high correlation between OBQ11-T and WHOQOL-T (r=0.600); moderate between GH (r=0.586), PH (r=0.537), MH (r=0.524), EH (r=0.529); low correlation was found between SH (r=0.342). The correlations were statistically significant (p<0.05) (Table 3).

Table 3. Relationship between the OB and the QOL of caregivers of children with visual impairments

N=59	OBQ11-T **Mean/SD (12.37±6.70)**		
	Median (IQR)	**p**	**r**
1. WHOQOL-GH	50.00 (25.00)	0.001***	0.586
2. WHOQOL-PH	53.57 (25.00)	0.001***	0.537
3. WHOQOL-MH	54.16 (20.83)	0.001***	0.524
4. WHOQOL-SH	50.00 (33.33)	0.008**	0.342
5. WHOQOL-EH	46.87 (31.25)	0.001***	0.529
6. WHOQOL-T	50.00 (21.30)	0.001***	0.600

*p<0.05; **p<0.01; ***p<0.001; r: Spearman Correlation Coefficient; IQR: Inter Quartile Range; OBQ11-T: Occupational Balance Questionerrie; SD=Standard Deviation; WHOQOL: World Health Organization Quality of Life Scale Short Form. GH: General Health. PH: Physical Health. MH: Mental Health. SH: Social Health. EH: Environmental Health. T: Total Score

DISCUSSION

The main finding of the study is that there is a relationship between the QOL and OB of COC with VI.

In this study, we found that the OB of COC with VI correlated with the caregivers' total score and general health, physical health, mental health, social health, and environmental health scores of WHOQOL-BREF. A good OB and time use may be determinants of health and well-being. Caring for a visually impaired child may require different responsibilities than caring for other children with special needs. It has been reported that the difficulties experienced by COC with VI, in particular, are enormous, and sometimes the difficulties encountered are beyond the coping capacity of their families. Also, most parents of visually impaired children need financial resources to provide their children with a better standard of living (Ya-Otto, Tobias, & Mashego-Brown, 2018). In this study, few caregivers were working in paid job. It can lead to increased financial support needs for maintenance. This situation may have restricted the caregivers, who already have limited financial resources, from participating in occupations such as taking hobbies or participating in social activities. In a different dimension, employment is a fundamental element of an adult's life and not only generates income but also provides a sense of participation, role definition, and physical and mental stimulation (Wanberg, 2012). It has been shown that limitations in participating in productive activities can have a significant and negative impact on the overall quality of life (Extreme, & Rey, 2014).

Caring for a child with visual impairment may involve different needs. Some studies have shown that care needs and burnout may increase depending on the child's vision level. It was stated that as the vision level of the child decreases, the need for support in daily life may increase, and the physical activity level of the child may decrease (Braich, Lal, Hollands, & Almeida, 2012; Perkins, Columna, Lieberman, Bailey, 2013). However, Houwen et al. stated that children's gross motor skill levels and physical capacities are not related to their visual level (Houwen et al., 2007). This may suggest that children's physical support needs in daily life are independent of their visual level. In this study, it was found that there was no statistically significant difference between the COC with blindness and LV both in their QOL Total and OB. However, in further studies, grouping children according to their visual acuity levels and comparing the OB and QOL of the caregivers can enable us to see the effect of vision more clearly.

Another finding of the study is that the OB scores of the caregivers are relatively low. Donovan et al. (2005) stated that families of children with special needs were isolated from activities involving social contact, and therefore they had difficulty coping with their emotional burden (Donovan, VanLeit, Crowe, & Keefe, 2005). Dalvand et al. reported that COC with cerebral palsy had difficulties in participating in personal care and leisure time activities and coping with this process during the long rehabilitation period (Dalvand et al., 2015). Sola-Carmona et al. stated that the well-being of caregivers with children affected by visual impairment is negatively related to reduced leisure time participation (Sola-Carmona et al., 2016). Barrozo et al. stated that caring for a visually impaired person leads to losses or changes in professional roles, especially among working caregivers. It showed important results such as changes in the life routines and roles of the caregiving process (Barrozo, Rubo Nobre, & de Cássia Into Montilha, 2015). There may be factors affecting the OB levels of the caregiver’s children with VI and that may require to support from other caregivers. The child's lack of vision and the need for support in daily life may cause the parent to devote most of his time and activities to his child. Caregivers who feel the need to constantly monitor and protect their children at home or in the social environment may have difficulty spending time for themselves. Even if children’s levels of physical independence and participation in activities of daily living are high, environments outside the home are particularly fraught with risks for children with VI. Even if the child can go out alone, unfortunately, the accessibility resources to the social environment are insufficient. Therefore, families often have to be with their children in all situations. For this reason, caregivers may often use their time to continue and be with their children, rather than devoting their time to different activities that may be valuable to them.

Another finding of the study was that the quality of life levels of caregivers was at low levels. It was determined that the quality of life score was at the level of 50 percent by the caregivers at both the total level and in the subtests. There is growing research interest in the quality of life of parents of children with VI. However, different opinions have been put forward on what affects the quality of life of these caregivers. The relationship between the severity of visual impairment or the presence of comorbidities and its impact on the family remains controversial, and there are inconsistent results in published literature (Lupón, Armayones, & Cardona, 2018). Some authors conclude that both factors have a negative impact, while others emphasize comorbidity rather than the true severity of VI (Sola-Carmona et al., 2016; Tröster, 2001). Again, some studies have stated that factors such as care burden, burnout, and stress negatively affect the quality of life of these individuals (Fathizadeh et al., 2012; Speedwell et al., 2003). Based on the data of this study, we think that the quality of life of individuals may have also been affected by their occupational imbalances. A good and balanced daily life cycle can increase the well-being of individuals and support the habits of a quality and healthy life. We think that the quality of life, balance of activity and efficient use of the time of COC with VI should be further investigated by occupational therapists.

Key Findings

This study is the first to evaluate the relationship between the QOL and OB of COC with VI. The findings of the study revealed the support needs of these caregivers. These caregivers, which are rarely mentioned in the literature and sometimes assume the role of being the eyes of their children, have distinct needs like their children. We think that there are many issues that occupational therapists should support and investigate about the families such as lifestyle changes, OB education and time management.

Limitations

Data were collected with a survey method in a local region of Turkey, collecting data from different locations could offer a different perspective. In addition, the global COVID-19 pandemic at the time of the evaluations may have affected the answers of the families. Another limitation was the inability to compare the QOL and OB according to children’s functional vision levels.

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Statement of contributorship

All authors contributed to the development of the study methodology, data collection and analysis. All authors participated in writing, reviewing and editing the manuscript, and approved the final version.

Conflict of interest

The authors declare that there is no conflict of interest.

Ethics Committee

The study was approved by the local institutional ethical board (Hacettepe University Non-Interventional Clinical Research Ethics Committee, (registration number GO 20/1093) and conducted in consideration of Helsinki's Declaration principles.

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