Quality of Life and Psychological Distress of Caregivers' of Stroke People

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Abstract

Purpose: Caregivers play a substantial role on support at stroke survivors after acute hospitalization. The aims of the current study were: to determine the quality of life of caregivers of patients with stroke, and to evaluate the predictors of quality of life in caregivers.

Methods: It is a cross-sectional study including 150 caregivers of patients with haemorrhagic or ischemic stroke. Participants completed the Greek version of the 12-item Short Form Health Survey assessing caregivers' quality of life. Caregiver burden was measured with the Revised Greek Bakas Caregiving Outcomes Scale, and psychological distress was screened with Greek Hospital Anxiety and Depression Scales.

Results: A highly negative correlation was found between anxiety (r=0.56) and depression (r=0.59) with physical and mental health (r=0.44, 0.66, r=respectively) from quality of life subscales Physical Component Summary and Mental Component Summary scales.

Physical health was influenced by caregivers' health problems ($p<0.0005$), type of stroke ($p=0.014$), anxiety ($p=0.056$), depression ($p=0.024$). Mental health was influenced by caregivers' health problems ($p=0.051$), burden, anxiety and depression ($p<0.0005$, respectively).

Conclusions: Caregivers of people with stroke experience mental disorders and burden negatively affecting their quality of life. Therefore, there is a need to implement strategies which should aim to the management of these problems for the welfare of both patients and their caregivers.

Keywords: stroke, burden, informal caregivers, anxiety, depression, quality of life

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INTRODUCTION

Caregivers play a substantial role on support at stroke survivors after acute hospitalization. The provision of care has negative consequences resulting in a reduction of caregivers' physical and mental health(1). Furthermore, caregivers of patients with neurological disorders are at high risk of depression, isolation, burden and poor quality of life(2-4).

However, contrary to other chronic diseases, the onset

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of stroke appeared sudden, leaving both the patients and their carers to cope with its harmful consequences(1,5,6). Informal caregivers/carers play a substantial role on support at stroke survivors after acute hospitalization(7,8). Informal caregivers are not paid and usually are relatives, partners, and friends(8,9). They provide care to their relatives offering their assistance with activities of everyday activities (dressing, walking); they may also support their loved ones and they often determine long-term outcomes(8,10-12). In the beginning of the disease, they have to overcome the initial shock of the event, to reconsider their values and to amend their lives and the lives of their families, so that they can provide the appropriate care.

Strong association has been found between mental disorders in carers with their burden due to severe disability of patients after stroke; depression and anxiety and the impact of depressive symptoms on caregivers' physical health presented high; the increased rates of depression in caregivers, ranging between 34-52%, due to reduced social activity of the caregivers, patients' functional disability and level of dependence(7). Caregivers frequently experience high levels of anger and stress which may lead to harmful behaviors such as excessive alcohol consumption. As caregivers have less personal time they have no time to devote to other family members, for social life, shopping, or doing their housework(13).

Quality of life (QOL) is a complex, multidimensional construct and existing measures of QoL include a broad range of domains. In addition, it is an important indicator to determine the effectiveness of treatment and rehabilitation(14). Patients' health as well as the provision of care adversely affects caregivers' quality of life(7,15-17). In a study among 56 caregivers of patients with stroke found that quality of life was poor with negative prognostic factors age and the patient's quality of life, and the role of caregiver. As positive prognostic factors were satisfaction from the relationship with the patient and the care provider rewards. Caregivers who considered their relationship with the patient less balanced, experienced significantly higher burden related with those who perceived their relationship as equal(18). The caregivers of stroke patients especially those in severe condition experience high levels of burden which may affect their quality of life(19-21). The hypothesis of the present study was that there is a strong relationship between psychological distressing symptoms, burden and quality of life in carerers' of people with stroke. Therefore, the aims were to asses the above hypothesis as well as to investigate the factors that could influence caregivers' quality life.

METHODS

Materials and methods

The study was conducted in Filoktitis Center of Recovery and Rehabilitation, with the medical team "Egersis", Attiki, Greece, between Jenuary 2015 to June 2015.

Participants

Participants in this study were selected after meeting the inclusion criteria for participation. It was consisted of 150 informal caregivers of individuals with stroke and the data collection was conducted through a questionnaire to record caregivers' and stroke survivors' social and demographic characteristics. The stroke survivors have had the stroke for a minimum of 6 weeks. Inclusion criteria included: Informal Caregivers; caregivers of patients with haemorrhagic or ischemic stroke; written informed consent from all participants. Criteria for exclusion were: formal caregivers, age <18 years of age. The study has been approved by the Hospital's ethics committee according to Declaration of Helsinki Principles and to guidelines for Good Clinical Practice. The ethics committee of the Filoktitis medical Rehabilitation Center gave the permission and approved the study.

Instruments

The National Institutes of Health Stroke Scale, (NIHSS) is a measure to describe the impairment of a person as a consequence of the stroke. It consists 11 items (0=normal-4=severe impairment). The minimum score is 0 and the maximum is 4221.

One trained researcher-physiotherapist obtained the necessary information from the caregivers and the stroke patients, using the following instruments:

For the assessment of caregivers' QoL, the 12-item Short Form Health Survey (SF-12) was used(22). It is a valid and reliable questionnaire, brief evaluating overall health status. It is consisted of 12 items of an abbreviated version of the Medical Outcomes Study 36-Item Short-Form Health survey. It results in two scales of mental and physical functioning – components (Physical Component Summary (PCS) and Mental Component Summary (MCS) scales. Cronbachs' α for both scales were 0.86 for PCS and 0.79 for MPS.

For anxiety and depressive symptoms the Greek Hospital and Anxiety Scales (G-HADs) have been used. HADs is a self-assessment mood scale(23,24). It is a brief self-report 14-item scale screening depression and anxiety in two different subscale scores (G-HADS-D, G-HADS-A) with higher scores indicate poorer outcomes with Cronbach's alphas: 0.77 for G-HADS-D and 0.86 for G-HADS-A. The cut off scores depicted mild A-D: 8-10, scores 11-14 as moderate A-D and ≥15 score as severe A-D.

Caregivers' burden was measured with the Revised Greek Bakas Caregiving Outcomes Scale (G-BCOS). It is a 15-item questionnaire measures changes of caregivers' perceptions as a consequence of the provision of their care for their patient. Its items includes social functioning, physical health and subjective well-being and the higher total scores show positive caregiver outcomes(25). The Cronbach's alpha coefficient for the total Greek BCOS score was 0.83.

Statistical analyses

Data were expressed as mean±S.D for continuous variables and as percentages for categorical data. The Kolmogorov-Smirnov test was utilized for normality analysis of the parameters.

Bivariate analyses were made by using the Student t-test and One-way ANOVA to analyze the relation between the dependent variables (SF-12 subscales: PCS-MCS) and the quantitative variables. Pearson correlation coefficients were used to analyze the relation between the dependent variable and the qualitative measures.

Multiple linear regression analysis with enter method using only the independent variables with $p<0.20$ in bivariate analysis was performed to determine the strongest predictots of dependent variables. All assumptions of linear regression analysis, homoscedasticity, linearity, normality and independence of error terms respectively and multicollinearity of quantitative and qualitative independent variables, were examined.

A p-value of <0.05 (two sided) was used to denote statistical significance . All analyses were carried out using the statistical package SPSS vr. 17.00 (Statistical Package for the Social Sciences, SPSS Inc., Chicago, Ill., USA).

Results

Descriptive statistics

Socio-demographic variables for caregivers and the patients have been presented in tables 1 and 2.

The majority of the caregivers were female (67.3%). From the participants 38.7% were parents, 34% spouses and the rest of them were brothers/sisters (9.3%), children (9.3%) and other relatives (8.7%). The mean age of caregivers was 49.42 (±14.33) (Table 1.). From the patients 63.3% were male. The majority of the participants were on average (52%) or severe condition (36.7%) according to NIHSS21. The majority (71.3%) had ischemic stroke while the rest of them were diagnosed with haemorrhagic stroke (28.7%). Patients' mean age was 61.85(±16.91) (Table 2.).

The mean scores for burden measured by G-BCOS were 57.3 (±18.22), 10.84(±4.93) for anxiety and 8.77(±5) for depression and the means for SF-12 components were: 15.06(±3.84) for PCS and 14.95(±4) for MCS.

Results have shown that the less burden caregivers experienced the more anxiety ($r=-0.53$, $p<0.0005$) and depression ($r=-0.64$, $p<0.0005$) have presented. In addition, significant correlations were found between PCS with G-BCOS score ($r=0.44$, $p<0.0005$), HAD-Anxiety ($r=-0.56$, $p<0.0005$) and HAD-Depression ($r=-0.59$, $p<0.0005$). Moreover, MCS was significantly correlated with G-BCOS score ($r=0.69$, $p<0.0005$), HAD-A ($r=-0.75$, $p<0.0005$) and HAD-D ($r=-0.8$, $p<0.0005$) (table not included).

Univariate Analyses

Factors significantly related to PCS were: family status; single caregivers revealed better quality of life concerning PCS than married caregivers; caregivers with children and those who provided care more than 3 hours per day had poorer PCS than caregivers without children or those that care their patient less than 3 hour daily (Table 3). The strongest associations have been found between PCS and relationship with the patient ($p<0.0005$) where parents and siblings had better PCS than spouses; then,

Table 1. Caregiver's sociodemographic characteristics

		N	%
Caregiver's gender	Male	49	32.7
	Female	101	67.3
Education	Primary	14	9.3
	High School	53	35.3
	University	83	55.3
Family Income	<10.000	38	25.3
	10.000-20.000	61	40.7
	>20.000	51	34.0
Family Status	Married	101	67.3
	Unmarried	36	24.0
	Divorced	10	6.7
	Widowed	3	2.0
Children	No	46	30.7
	Yes	104	69.3
Profession	Civil servant	23	15.3
	Private Employee	38	25.3
	Freelance	44	29.3
	Unemployed	24	16.0
	Pensioner	21	14.0
Relationship with the patient	Parents	58	38.7
	Spouses	51	34.0
	Siblings	14	9.3
	Children	14	9.3
	Other	13	8.7
Time spend for caregiving (daily)	> 1h	17	11.3
	1-3 hrs	51	34.0
	<3 hrs	82	54.7
Health problems	No	108	72.0
	Yes	42	28.0
	Median ± SD	Min	Max
Caregiver's age	49.42±14.33	20	86
Caring duration	18.57±18.84	1	72

Table 2. Patients' sociodemographic characteristics

		N	%
Patient's gender	Male	95	63.3
	Female	55	36.7
Degree of stroke severity*	Mild	17	11.3
	Moderate	78	52.0
	Severe	55	36.7
Stroke type	Ischemic	107	71.3
	Hemorrhagic	43	28.7
Ability to communicate	Excellent	45	30.0
	Satisfactory	57	38.0
	Mild	41	27.3
	None	7	4.7
	Median ± SD	Min	Max
Patient's age	61.85±16.91	19	92
Time course of stroke	23.48±20.74	6	90

* Stroke severity was assessed with the National Institutes of Health stroke Scale (NIHSS score) according to the stroke severity into 3 groups: mild stroke (1-4), Moderate: (5-15), Severe: (16-)

caregivers' health problems (16.32±3.12) significantly related with poorer PCS (11.8±3.63, p<0.0005). Similarly, those caring patients with hemorrhagic stroke reported better quality of life according to their PCS than those caring patients with ischemic stroke (16.05±3.2, 14.66±4.01, p=0.046 respectively) (Table 4).

The mean scores for the daily care were inversely correlated to quality of life concerning MCS (17.53±3.78, 16.08±3.61, p<0.0005 respectively). Statistically significant differences were also found between caregivers' health problems and MCS where the more health problems caregivers experienced the lower scores on MCS reported (Table 5).

Table 6, shows the association between patients' clinical factors and MCS. Disease severity and patients' inability to communicate had significantly lower caregivers' MCS (p=0.037, p=0.001 respectively) (Table 6.)

Multivariate analyses

In the multivariate analyses caregivers' health problems, type of stroke (ischemic vs. hemorrhagic) and depressive symptoms of caregivers affected PCS while anxiety tend to influence PCS (Table 7).

Then, in table 8 one can see the factors that influenced MCS. Caregivers with health problems tend to experience poorer QoL concerning their mental status than those without health problems (p=0.05). The strongest predictors of MCS were caregivers' burden as well as anxiety and depression (p<0.0005 respectively).

Discussion

The current study highlights the psychological distress and burden as well as their impact on caregivers of stroke patients' quality of life.

The stroke is the most common chronic neurological disease, and one of the main causes of disability morbidity and mortality worldwide(26,27). Rigby et al.(28), have found that in caregivers of stroke patients age, male gender, poor mental health and functional disability were significant correlates with caregiver burden. Similarly, in another study with stroke caregivers eliminated depressive symptomatology has been found at the follow up 3 months after the initial assessment(29). Therefore, the initial period of diagnosis and hospitalization seemed to be the most essential concerning the caregivers' mental health(2).

Furthermore, the bonds between caregiver and the patient and thus their relationship have an effect on their quality of life; more specifically, mental and physical health as well as depressive and anxiety symptomatology

Table 3. Univariate analysis of SF12-Physical Component Summary scale (PCSs)

		Median	SD	p-value
Caregiver's gender	Male	15.88	3.39	0.069
	Female	14.66	4.00	
Education	Primary	13.36	3.84	0.064
	High	14.55	3.94	
	University	15.67	3.68	
Family income	< 10.000 e	14.03	3.71	0.106
	10.000-20.000 e	15.11	4.05	
	>20.000 e	15.76	3.58	
Family status	Married	14.64	3.84	0.048
	Unmarried	16.39a	3.42	
	Divorced	15.90	3.93	
Children	No	16.43	3.44	0.003
	Yes	14.45	3.86	
Profession	Civil Servant	14.65	4.24	0.572
	Private Employee	15.13	3.96	
	Freelance	15.23	3.58	
	Unemployed	14.96	3.86	
	Pensioner	14.10	3.77	
Relationship with the caregiver	Parents	16.09c	3.38	<0.0005
	Spouses	13.27	4.16	
	Siblings	17.21c	3.36	
	Children	14.57	3.11	
	Other	15.69	3.01	
Time spend for caregiving (daily)	<1h	16.53b	3.16	0.004
	1-3 hrs	16.08b	3.65	
	>3 hrs	14.12	3.86	
Health problems	No	16.32	3.12	<0.0005
	Yes	11.81	3.63	

a: $p<0.05$ vs married, b: $p<0.05$ vs >3 hrs, c: $p<0.05$ vs spouses

Table 4. Univariate analysis of SF12-Physical Component Summary scale (PCSs)

		Median	SD	p-value
Patient's gender	Male	14.86	3.87	0.411
	Female	15.40	3.80	
Degree of stroke severity	Mild	15.25	4.42	0.630
	Moderate	15.18	3.77	
	Severe	14.71	3.79	
Stroke type	Ischemic	14.66	4.01	0.046
	Hemorrhagic	16.05	3.20	
Patient's ability to communicate	Excellent	15.78	3.57	0.064
	Satisfactory	15.54	3.58	
	Mild	13.85	4.03	
	None	13.57	5.06	

of the one member has been associated with the others' respectively(30-34).

The majority of the participants were females as it was expected because in many societies women engage full in their family members with chronic diseases care(6,15,35,36). However, gender was not associated with poor mental health or burden, similar to the study of Ain et al.(37). In addition, the vast majority of primary caregivers regarding their relationship with their patients were parents or spouses.

Caregivers seemed to be at increased risk for psychological distress, burden and other health problems(38). They are under considerable stress, which is evident right after the stroke, and is significantly increased as the time passes by. The role of the caregiver in the management of stroke patients is important, and the emphasis should be on their quality of life, which is influenced by their satisfaction with life, psychological, social and physical functioning as well as the burden experienced due to their role(22,25,38). Many authors have argued that the provision of care negatively affects the caregivers QoL(7,20,22). In this context, descriptive analysis showed that caregivers experienced medium scores of anxiety and depression than the prevalence in other countries(40,41). In addition, high correlations were explored between burden anxiety and depression with QoL components(41).

Univariate analysis revealed that unmarried caregivers experienced better physical health than married or divorced caregivers (p=0.048). Similarly, caregivers without children had better physical health than those with children (p=0.003). The current findings may explained by the fact that caregivers with families have less time to devote to themselves and their families because of their burden providing care to their patients(15,42).

Time of caring is essential in those who provide care at their patients as the caregivers are able to learn and cope with all the problems of caring as the time passing by(19). The spending time of care of stroke patients per day has been related to the caregivers' burden and their quality of life(40,43-45). Furthermore, caregivers' burden eliminated when caregivers have free time for their activities(42) as it seemed that very frequently those who spent their time for caring they do not have personal time for themselves and their activities, experiencing difficulties in managing their own family life and frequently give up their jobs(46). Similar to the above findings in our study it has been revealed that more than 3 hours of care daily associated with poor quality of life concerning physical and mental domains (p= 0.0005 respectively) than those who spent less than 3 hours of care per day.

From the caregivers some of them revealed health problems (28%) with the healthy individuals to perform better mental health related with those with health problems as the performance status and their general health related with their burden and poor QoL(7,44).

Good quality of life of patients with stroke and their carers has been associated with lower caregivers' burden(47). Regarding our findings, the largest proportion of the patients had suffered from ischemic stroke, as

Table 5. Univariate analysis of SF12-Mental Component Summary scale (MCSs)

		Median	SD	p-value
Caregiver's gender	Male	15.33	3.62	0.428
	Female	14.77	4.18	
Education	Primary	15.21	3.96	0.504
	High	14.53	3.83	
	University	15.24	4.12	
Family income	< 10.000 e	13.84	3.90	0.109
	10.000-20.000 e	15.57	3.99	
	>20.000 e	15.04	3.98	
Family status	Married	14.66	3.95	0.183
	Unmarried	16.08	4.04	
	Divorced	15.10	3.54	
Children	No	15.70	4.15	0.131
	Yes	14.63	3.90	
Profession	Civili Servant	14.35	4.45	0.946
	Private Employee	14.89	4.21	
	Freelance	15.20	3.64	
	Unemployed	15.00	3.83	
	Pensioner	15.14	4.30	
Relationship with the caregiver	Parents	15.29	3.95	0.109
	Spouses	13.82	3.89	
	Siblings	16.64	4.29	
	Children	15.29	4.08	
	Other	15.69	3.68	
Time spend for caregiving (daily)	<1h	17.53a	3.78	<0.0005
	1-3 hrs	16.08 a	3.61	
	>3 hrs	13.84	3.92	
Health Problems	No	15.45	3.75	0.013
	Yes	13.67	4.38	

a: $p<0.05$ vs >3 hrs

expected since it is the most common and accounts for 80-85% of episodes(48). The type of stroke correlated with the physical activity component as patients with hemorrhagic stroke have better physical health ($p=0.046$) probably because they may not have so many symptoms of the incident, which helps to better quality of life as the patient does not exclusively depend on the caregiver(49). Similarly, the severity of the disease seemed to be related with the caregivers quality of life as the severe patients' condition and their inability to communicate have been associated with carers' poorer mental component scores ($p=0.037$, $p=0.001$, respectively) consistent to other studies(7,19,50,51).

Table 6. Univariate analysis of SF12-Mental Component Summary scale (MCSs)

		Median	SD	p-value
Patient's gender	Male	14.80	3.81	0.539
	Female	15.22	4.32	
Degree of stroke severity	Mild	17.18	4.11	0.037
	Moderate	14.90a	4.04	
	Severe	14.35a	3.73	
Stroke type	Ischemic	14.74	4.03	0.300
	Hemorrhagic	15.49	3.91	
Patient's ability to communicate	Excellent	16.31	3.94	0.001
	Satisfactory	15.25	3.75	
	Mild	13.73b	3.92	
	None	11.00b,c	2.58	

a: p<0.05 vs mild, b: p<0.05 vs excellent, c: p<0.05 vs satisfactory

Table 7. Multivariate analysis of SF12-Physical Component Summary scale (PCSs)

	Referrence category	Beta	SE	p-value
Caregiver's gender	Male	-0.275	0.507	0.589
Caregiver's age	---	-0.033	0.025	0.195
Education	Primary-High	-0.369	0.521	0.481
Income (>10.000 e)	<10.000 e	0.697	0.567	0.221
Family status (Unmarried)	Married	-0.684	0.672	0.311
Children	No	-0.817	0.776	0.294
Relationship with the patient (other)	Spouse	0.425	0.596	0.477
Health problems	No	-2.833	0.602	<0.0005
Time spend for caregiving daily (>3hrs)	<3hrs	0.134	0.499	0.788
Patient's ability to communicate (Mild-None)	Excellent-Satisfactory	-0.633	0.536	0.240
Stroke type (Hemorrhagic)	Ischemic	1.342	0.538	0.014
Patient's age	---	0.013	0.015	0.394
G-BCOS	---	0.004	0.016	0.807
HAD Anxiety	---	-0.157	.082	0.056
HAD Depression	---	-0.198	0.087	0.024

Communication between caregivers and patients is one of the most important aspects of care; poor communication due to patients' cognitive and behavioral disturbances increase carers' burden and decrease their QoL(8,36,52,54).

The second aim of the current study was to identify independent determinants of caregivers' QoL regarding its components: physical and mental health. Despite the fact that in the univariate analysis there was a relationship

Table 8. Multivariate analysis of SF12-Mental Component Summary scale (MCSs)

	Reference category	Beta	SE	p-value
Caregivers' age	---	-0.033	0.020	0.101
Income (>10.000 e)	<10.000 e	0.307	0.444	0.490
Family status (Unmarried)	Married	-0.363	0.547	0.508
Children	No	0.137	0.621	0.825
Relationship with the patient (other)	Spouse	-0.015	0.487	0.975
Health problems	No	-0.964	0.490	0.051
Time spend for caregiving daily (>3hrs)	<3hrs	-0.306	0.409	0.456
Degree of stroke severity (Moderate-Severe)	Mild	-0.363	0.598	0.545
Patient's ability to communicate (Mild-None)	Excellent-Satisfactory	-0.157	0.439	0.721
G-BCOS	---	0.054	0.013	<0.0005
HAD Anxiety	---	-0.244	0.065	<0.0005
HAD Depression	---	-0.315	0.069	<0.0005

between hours of daily care and QoL, however, other factors seemed more important that influence caregivers' QoL in the multiple regression analyses.

The quality of life of carers of people with stroke depends on the burden experienced, which in turn was influenced by patients' psychological, social and physical functioning, as well as by carers' health status. Moreover, caregivers with poor general health status experienced higher burden and poorer quality of life(17,41,44) in agreement with our results where caregivers' health problems seemed to influence their QoL in both domains physical and mental health.

Previous findings reported high depressive symptoms among caregivers of patients with stroke and the burden that they experienced was correlated significantly with poor quality of life, consistent to our findings in multivariate analyses where caregivers' health problems and burden showed deficit in mental health domain but not in physical health indicating the probable strong relationship between burden and carers' psychological health; the detrimental effects of caring in physical domain, are frequently less intensive than caregivers' psychological effects(54).

In addition, caregivers with patients with hemorrhagic stroke appeared with better QoL concerning physical health than those provided care in patients with ischemic stroke. One possible explanation for the current finding might stem from the fact that these caregivers might not have so many consequences from the incident and thus better QoL as their patients may not depend exclusively on them(50).

The increased rates of depression these caregivers, ranging between 34-52%, due to factors such as patient functional disability, reduced social activity of the caregiver and the patient's level of dependence(7). Furthermore, other factors that may lead to increased rates of depression include fatigue, inadequate rest and spiritual and mental challenges faced by caregivers(55-57). Similarly, in the multivariate analyses, the higher levels of depression seemed to influence the decrease rates of physical and mental health in caregivers' quality of life.

Another highly important predictor of caregivers' quality of life was anxiety similar to other findings(58,59). Increased anxiety during the first few months of stroke may stem from carers' concern about the prognosis of their patient, and uncertainty for the future(60.61).

It is worthnoting to state the importance of psychological support and education for the caregivers and the stroke survivors. Caregivers participated in psychoeducation sessions expressed less burden, experienced lower rates of anxiety and depression(62,63). High quality stroke services are needed urgently for the welfare of patients and their caregivers(37); education, self-management programs and caregivers' active participation are crucial for the effective care of the patients and thus improvement of their quality of life(63,64). Psychotherapy should also be helpful for the caregivers to manage their burden and cope with psychological distress reducing the levels of anxiety and depression.

"Compliance with Ethical Standards"

Disclosure of potential conflicts of interest

"The authors declare that they have no conflict of interest".

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