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Quality of life of users of long-term health care

Kvalitet života korisnika dugoročne zdravstvene njege

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ABSTRACT

Objective. Long-term care represents a series of health and social care services that are provided at home or in an institutional environment to people with reduced functional capacity (reduced physical and/or cognitive abilities) who need support in performing daily activities, and who depend on the help of others for a long time period. The goal of the research was to examine the quality of life of users with long-term health care, with a special focus on comparing the quality of life between people placed institutionally and outside of the institution.

Methods. The research was designed according to the principle of a cross-sectional study. In the research, a general questionnaire and a scale for assessing the quality of life Short Form 36 Health Survey (SF-36) were used. Among the statistical tests, the $\chi 2$ square test was used. The usual value of p<0.05 was taken as the level of statistical significance.

Results. Subjects who were institutionalized had statistically significantly lower values of domains and summary scores of quality of life compared to subjects whose health care took place outside of institutions, whereby the difference was observed in physical functioning (p<0.001), social functioning (p=0.003) and mental health summary score (p=0.015).

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APSTRAKT

Cilj. Dugoročna njega predstavlja niz usluga zdravstvene i socijalne zaštite koje se pružaju u kući ili u institucionalnom okruženju osobama sa smanjenom funkcionalnom sposobnošću (smanjenje fizičkih i/ili kognitivnih sposobnosti) kojima je potrebna podrška u obavljanju svakodnevnih aktivnosti, a koje zavise od tuđe pomoći u dužem vremenskom periodu. Cilj istraživanja je bio ispitati kvalitet života korisnika dugoročne zdravstvene njege, sa posebnim osvrtom na upoređivanje kvaliteta života između korisnika smještenih institucionalno i van institucije.

Metode. Istraživanje je dizajnirano po principu studije presjeka. U istraživanju su korišćeni opšti upitnik i skala za procjenu kvaliteta života Short Form 36 Health Survey (SF-36). Od statističkih testova korišten je x2 kvadrat test. Kao nivo statističke značajnosti uzeta je uobičajena vrijednost p<0,05.

Rezultati. Ispitanici koji su bili institucionalno smješteni imali su statistički značajno niže vrijednost domena i sumarnih skorova kvaliteta života u odnosu na ispitanike kod kojih se zdravstvena njega odvijala vaninstitucionalno, pri čemu je razlika uočena u fizičkom funkcionisanju (p<0,001), socijalnom funkcionisanju (p=0,003) i sumarnom skoru mentalnog zdravlja (p=0,015).

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Conclusion. Users of long-term health care placed in an institution had significantly worse physical functioning, a higher level of limitations due to physical problems, worse general health, a lower level of social functioning, as well as mental health.

Key words: delivery of health care; long-term care; quality of life.

Zaključak. Korisnici dugoročne zdravstvene njege smješteni u instituciji imali su značajno lošije fizičko funkcionisanje, veći nivo ograničenja zbog fizičkih problema, lošije opšte zdravlje, niži nivo socijalnog funkcionisanja, kao i mentalnog zdravlja.

Ključne riječi: pružanje zdravstvene zaštite; dugotrajna njega; kvalitet života

INTRODUCTION

Long-term care is a series of health and social care services that are provided at home or in an institutional environment to people with reduced functional capacity (reduced physical and/or cognitive abilities) who need support in performing daily activities, and who depend on the help of others for a long time period^{1,2}.

Today, we distinguish several models of providing long-term care to patients. The basic elements of the long-term care system are the philosophy of the system in terms of who bears the responsibility (family or the state), the way the state organizes care (cash benefits, services, combination), financing of the care delivery system and the degree of generosity of state support. All these elements are complicated to take into account at the same time, so many authors resorted to the classification of long-term care based on only one or two criteria³. According to the classification most often used in practice, long-term care can be formal (institutional and non-institutional) and informal.

Although the profile of patients who need long-term health care is different and includes the young and the elderly of different genders and health conditions, most often long-term health care is required by the elderly. Aging is a physiological process during which biological, psychological and sociological changes occur, and according to certain theories, genetics play the most important role in the process of biological aging⁴. Defining age is not only a matter of chronological age and functional abilities, but also implies a relationship between the quality of one's life, the value system and the characteristics of the environment in which that person lives⁵.

The increase in the number of elderly people, especially those over 80 years old, brings great changes. Retirement, financial dependence, social exclusion, loss of loved ones and higher levels of disability resulting from chronic diseases, and the result is an increase in the need of the elderly for family support, as well as a strong increase in the demand for institutional health care, which provides care for these people and takes care of them 24 hours a day⁶.

In the last few decades, our society has undergone great and sudden changes in the forms and structure of the family. The family used to be traditional, patriarchal and rural, which has been replaced by the industrial family. This change led to the emergence of a better quality of life for the younger generations, but at the same time it also brought numerous problems, especially in terms of attitudes towards the elderly population of society. The large rural families of the time provided adequate protection and care for their elderly members, however, modern families, with the simultaneous process of daily reduction, are increasingly facing difficulties in providing care and protection for the elderly. Precisely because of this, today we cannot expect families to be able to independently provide adequate care for the elderly, so the process of transferring this care for the elderly outside the family is increasingly present. Such care is increasingly provided by homes for the elderly and the infirm, where elderly people who are unable to take care of themselves or their families do not have adequate resources and conditions for providing care to an elderly person are accommodated. This is precisely why the institutional placement of elderly people, as the dominant form of care for the elderly, is often the only alternative^{6,7}.

Quality of life is a comprehensive overall satisfaction/dissatisfaction with one's life. The World Health Organization defines quality of life as an individual's perception of his own position in life from a cultural, social, physical and psychological aspect, in relation to the goals, standards and expectations that apply in these systems. Although the terms health status and well-being are often used as synonyms for quality of life in the literature, they are only individual aspects of a concept that is much more comprehensive⁸.

In addition to objective factors, the quality of life is also influenced by the subjective perception and assessment of physical, social, material and emotional well-being, personal development and purposeful activity. Research shows that patients who are beneficiaries of long-term health care have a worse quality of life, because their impaired state of health affects all segments of life8, and also, research shows that a poorer quality of life is a significant indicator of more frequent mortality and limitations in physical functioning9.

However, in addition to health problems that can affect the quality of life of institutionalized patients, the quality of life can be affected by a large number of external factors, primarily a change in the living environment (for example institutional placement), rigid daily routines and changes in social interaction patterns^{9,10}. However, due to the high frequency of chronic diseases that lead to physical and cognitive limitations at this age, the assessment of the quality of life of the elderly

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population is usually reduced to the health-related quality of life and/or the quality of the health care provided.

The aim of the research was to compare the quality of life of users of long-term health care who were institutionalized and non-institutional.

SUBJECTS AND METHODS

The research was carried out according to the type of cross-sectional study in public institutions: PHI Community Health Center "Dr Isak Samokovlija" Goražde, and in PI "Home for old and infirm persons" in Goražde, in 2022. The sample consisted of users of these institutions. The study included 100 respondents of long-term health care users. The respondents were divided into two groups. The first group consisted of 50 respondents who are patients of the "Dr Isak Samokovlija" Goražde Health Center, and are users of long-term non-institutional home health care. The second group consisted of 50 respondents who are institutionalized and are beneficiaries of long-term health care at the "Home for Aged and Infirm Persons" in Goražde. Respondents of both sexes, aged over 65, participated in the research.

The respondents were selected using a random sampling method, based on their arrival at the Goražde Community health center or attendance at the Home for old and infirm personson the day of the examination. The examination lasted from June to August 2022. Before starting the research, written consent was obtained from the competent directors of the institutions. Decision numbers: 208 and 04-30-9-807-1. Participation in the study was voluntary, and the survey was anonymous.

The data was collected by surveying. The survey questionnaire consisted of questions for collecting demographic data, socioeconomic data, as well as a standardized scale for assessing the quality of life Short Form 36 Health Survey (SF-36)^{11,12}. The general questionnaire included questions about gender, age, marital status, satisfaction with monthly financial income, life satisfaction and satisfaction with non-institutional or institutional long-term health care. The SF-36 health survey is the most commonly used general questionnaire for assessing the quality of life of patients. The questionnaire is intended for self-assessment of mental and physical health and social functioning. It has 36 questions, of which 35 questions are grouped into eight areas or domains: physical functioning (PF), limitations due to physical health problems (RP), bodily pain (BP), general health perceptions (GH), vitality (VT), social functioning (SF), limitations due to emotional problems (RE), general mental health (MH).

In this research, the data were processed using the SPSS statistical software package. Of the statistical tests, the $\chi 2$ square test, a non-parametric test, was used. The data are presented in tabular form. As the level of statistical significance

of the difference, the usual p value was taken. Values less than 0.05 were considered statistically significant.

RESULTS

The study included 100 subjects aged 65 to 85, of whom 63 (63%) were women and 37 (37%) were men. Between the groups of respondents divided according to the place of accommodation where long-term health care took place, a statistically significant difference was observed in relation to the gender (p=0.023) and age (p=0.003) of the respondents, while no difference was observed in relation to marital status. There is a significantly higher number of male respondents who were institutionalized (74%) compared to non-institutionalized male respondents (52%). Also, there is a significantly higher number of elderly respondents (75 to 85 years old) who were institutionally housed (68%) compared to respondents of the same age group who were non-institutionally housed (38%) (Table 1).

Tabela 1. Distribution of patients by group according to place of accommodation where long-term health care took place in relation to gender, age and marital status

age and marrial status							
Socio-demographic characteristics	Institutional accommodation (n=50)		Non-institutional accommodation (n=50)		x2	p*	
	Number	%	Number	%			
Gender	Gender						
Male	37	74	26	52	12,342	0,023	
Females	13	26	24	48			
Age							
65-74 years	16	32	31	62	14,865	0,003	
75-85 years	34	68	19	38			
Marital status							
Married	18	36	29	58	2,379	0,076	
Single	3	6	3	6			
Widower/widow	29	58	18	36			

Table 2 shows the distribution of the quality of life (domains and summary scores) of all surveyed users of longterm health care according to the level of quality of life. 44% of respondents had poor physical functioning, 40% had good physical functioning, while 16% of respondents had excellent physical functioning. 47% of respondents had the lowest level of restrictions due to physical problems, 35% had a medium level of restrictions, while 18% of respondents had no restrictions due to physical problems. A high level of physical pain was experienced by 38% of respondents, a medium level by 44%, while a low level of physical pain was experienced by only 18% of respondents. 49% of users of long-term health care had a low level of general health, 37% of respondents had good general health, while 14% of respondents had excellent general health. Vitality was poor in 57% of respondents, good in 30%, while 13% of long-term health care users had excellent vitality. 38% of respondents had poor social functioning, 44% had good social functioning, while 18% of long-term health care users had excellent social functioning. 41% of respondents were highly restricted due to emotional problems, 49% had a medium level of restriction, while only 10% of respondents had a low level of restriction due to emotional problems. 35% of respondents had a poor level of mental health, 60% had a medium level, while 10% of respondents had excellent mental health. The summary scores showed that the physical health summary score (PCS) was poor in 35% of respondents, good in 60%, while it was excellent in only 5% of respondents. The mental health summary score (MCS) was poor in 27% of respondents, good in 60%, and excellent in 13% of long-term health care users (Table 2).

Tabela 2. Presentation of the distribution of the level of quality of life of respondents of second-term health care

Domains and summary scores	Level of quality of life (SF-36)					
CE 7C questionnaire	Bad		Good		Excellent	
SF-36 questionnaire	Number	%	Number	%	Number	%
Physical functioning	44	44	40	40	16	16
Limitations due to physical problems	47	47	35	35	18	18
Body pain	38	38	44	44	18	18
General health	49	49	37	37	14	14
Vitality	57	57	30	30	13	13
Social functioning	38	38	44	44	18	18
Limitations due to emotional problems	41	41	49	49	10	10
Mental health	35	35	55	55	10	10
*PCS	35	35	60	60	5	5
**MCS	27	27	60	60	13	13

^{*}PCS The physical health summary score;

It was observed that there is a statistically significant difference between the respondents in the average values of the domain and the summary scores of the quality of life in relation to the place of accommodation where the long-term health care took place. Respondents who were institutionalized had statistically significantly lower values of domains and summary scores of quality of life compared to respondents whose health care took place outside of institutions, where the difference was observed in physical functioning (40.50±14.06% vs 53, 70±19.94%, p<0.001), limitation due to physical problems (41.24±15.56% vs. 51.64±19.93%, p=0.005), general health (43.35±15, 15% vs. 50.41±19.62%, p=0.047), social functioning (43.10±16.10% vs. 54.75±21.26%, p=0.003), physical health summary score (37.67±6.20% vs. 50.39±10.74%, p<0.001), and the mental health summary score (44.87±11.82% vs. $51.83\pm16.01\%$, p =0.015). Table 5 shows the average values of all domains and summary quality of life scores for each group, as well as the average value of all respondents according to place of accommodation.

In the domains of physical pain, vitality, limitations due to emotional problems and mental health, no statistically significant difference was observed in the average values between the groups divided according to the accommodation where longterm health care took place (Table 3).

Tabela 3. Average values of domains and summary scores of the quality of life of respondents according to the place of accommodation where long-term health care took place

Domains and summary scores of the SF-36 (n=50)		Non- institutional accommodation (n=50)		In total (n=100)		p*	
questionnaire	AS	SD	AS	SD	AS	SD	
Physical functioning	40,5	14,06	53,7	19,94	47,1	18,4	<0.001
Limitations due to physical problems	41,24	15,56	51,64	19,93	46,44	18,54	0,005
Body pain	40,36	17,85	45,83	16,4	43,09	17,27	0,583
General health	43,35	15,15	50,41	19,62	46,88	17,79	0,047
Vitality	42,39	15,3	47.50	20,3	44,95	18,07	0,158
Social functioning	43,1	16,1	54,75	21,26	48,92	19,65	0,003
Limitations due to emotional problems	50,66	29,53	54,66	23,09	52,66	26,45	0,452
Mental health	47,72	15,24	48,14	14,77	47,93	14,93	0,889
*PCS	37,67	6,2	50,39	10,74	44,03	10,82	<0,001
**MCS	44,87	11,82	51,83	16,01	48,35	14,43	0,015

^{*}PCS The physical health summary score;

AS-average score; SD-standard deviation

No statistically significant difference was observed between the age groups of the respondents in the average values of any domain or summary score of the quality of life (Table 4).

Tabela 4. Average domain values and summary scores of the quality of life of long-term health care subjects according to age

	Age of the respondents				
Domains and summary scores of	65 to 74 years		75 to 85 years		p*
the SF-36 questionnaire	(N=47)	(N=47)		(N=53)	
	AS	SD	AS	SD	
Physical functioning	48,97	16,94	45,43	19,61	0,339
Limitations due to physical problems	49,44	19,73	43,77	17,16	0,127
Body pain	46,64	16,05	39,94	17,85	0,052
General health	45,40	16,03	48,19	19,28	0,438
Vitality	43,21	16,83	46,48	19,13	0,369
Social functioning	52,04	19,67	46,16	19,4	0,136
Limitations due to emotional problems	49,64	23,94	55,34	28,45	0,279
Mental health	47,27	16,09	48,5	13,95	0,683
*PCS	46,21	10,18	42,1	11,09	0,058
**MCS	47,57	11,87	49,04	16,45	0,615

^{*}PCS The physical health summary score;

There is a statistically significant difference between the respondents in the average values of physical and social functioning in relation to satisfaction with monthly financial income. Respondents who were satisfied with their monthly financial income had statistically significantly higher values in the domains of physical functioning ($40.18\pm15.84\%$ vs $49.29\pm19.97\%$, p=0.038) and social functioning (42.13 ± 19 , 38% vs. $50.28\pm19.91\%$, p=0.021), compared to respondents who were not satisfied with their monthly financial income. While the difference in the average values of other domains

^{**}MCS The mental health summary score

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AS-average score; SD-standard deviation

and summary scores between the groups of long-term health care respondents divided according to satisfaction with financial income was not observed (Table 5).

Tabela 5. Average domain values and summary scores of the quality of life of long-term health care respondents according to satisfaction with monthly financial income

D	Satisfa financia	p*			
Domains and summary scores of the SF-36 questionnaire	Satisfied (N=43)		Dissatisfied (N=57)		
	AS	SD	AS	SD	
Physical functioning	40,18	15,84	49,29	19,97	0,038
Limitations due to physical problems	46,2	17,6	46,61	19,37	0,915
Body pain	44,29	17,93	42,19	16,86	0,55
General health	46,05	17,19	47,51	18,36	0,686
Vitality	43,3	17,52	46,19	18,53	0,431
Social functioning	42,13	19,38	50,28	19,91	0,021
Limitations due to emotional problems	50,38	23,42	54,38	28,61	0,457
Mental health	47,93	14,71	47,92	15,23	1
*PCS	43,65	10,59	44,32	11,06	0,764
**MCS	46,71	13,09	49,59	15,36	0,326

^{*}PCS The physical health summary score;

AS-average score; SD-standard deviation

Subjects with a chronic disease had significantly lower values of the domain of physical functioning (39.27 ± 19.34) compared to subjects without chronic diseases (49.21 ± 15.87) (p=0.029). Between the groups of subjects divided according to the presence of chronic diseases, no statistically significant difference was observed in the average values of the remaining domains or summary scores of the quality of life (Table 6).

Tabela 6. Average domain values and summary scores of the quality of life of long-term health care respondents according to the presence of chronic diseases

	Presenc	p*			
Domains and summary scores of the SF-36 questionnaire	Yes (N=72)		No (N=28)		
	AS	SD	AS	SD	
Physical functioning	39,27	19,34	49,21	15,87	0,029
Limitations due to physical problems	42,05	17,62	50,01	20,63	0,233
Body pain	41,63	17,44	46,83	16,55	0,178
General health	48,18	18,09	43,55	16,87	0,245
Vitality	45,95	18,6	42,37	16,65	0,377
Social functioning	49,77	19,54	46,75	20,13	0,492
Limitations due to emotional problems	52,31	27,87	53,56	22,84	0,832
Mental health	48,02	14,37	47,67	16,57	0,917
*PCS	43,08	10,98	46,47	10,17	0,161
**MCS	49,05	15,31	46,56	11,93	0,441

^{*}PCS The physical health summary score;

DISCUSSION

The study was conducted on a sample of 100 long-term care users. Of the total number of respondents, the majority (63%) were male, while the remaining 37% of respondents were female. The average age of the respondents was 75 years. Of the total number of long-term health care respondents, 47% were married, 6% were single, while the remaining 47% were widowed. There is a significantly higher number of male respondents who were institutionalized (74%) compared to non-institutionalized male respondents (52%). Also, there is a significantly higher number of elderly respondents (75 to 85 years old) who were institutionalized (68%) compared to respondents of the same age group who were non-institutionalized (38%).

In order for treatment and long-term health care to be more effective, it is necessary to be familiar with the physical, psychological and social status of the persons to whom care is provided. The reason for this is that the impairment of any of these three components of the quality of life prevents the adequate provision of health care, especially if it is to be permanent. People with an impaired psychological component of the quality of life are not able to accept the disease, are less motivated to seek treatment or do not understand how necessary the application of health care is, while people with an impaired physical component due to the underlying illness do not have an adequate ability to function physically, have limitations due to physical problems, and their general health is impaired, which contributes to the emergence of psychological symptoms 10. This represents a vicious circle in which one type of symptom leads to the emergence of others or the worsening of existing ones, so it is very important that nurses/technicians recognize and assess the quality of life of health care users in time so that they can approach the patient in an adequate way.

Also, it is very important to assess the quality of life of users of long-term health care in the institution and outside the institution, and the main reason is that nurses/technicians would know what condition to expect when working in institutions and during home visits to patients who are provided with long-term health care, so that when providing care, they know which domains of quality of life can be impaired, that is exactly why our research was done. In this way, health care would be more precise, adequate and comprehensive and it would not only focus on the patient's health problem, but also on a holistic approach to the patient. Although research has shown that the quality of life in the elderly (over 65 years old) is significantly worse compared to the younger population of adults, due to the biological process of aging of the organism10,13,14, so far only a small number of studies have been conducted that examined the quality of life in the elderly populations of people who are users of long-term health care.

We found that the quality of life of all respondents is at a rather low level. The percentage of respondents who rated their physical and mental quality of life as excellent ranged

^{**}MCS The mental health summary score;

^{**}MCS The mental health summary score; AS-average score; SD-standard deviation

from 13% to 18%, and the remaining respondents rated their quality of life as bad or good. Research by Lim et al.15 conducted on a sample of 1,958 elderly people over 60 years of age in Sao Paulo, Brazil, showed that the average value of vitality in this sample was 64.4%, mental health 69.9% and general health 70.1%, while the highest scores were observed in limitations due to emotional problems (86.1%), social functioning (85.9%) and physical functioning (81.2%)15. Research on our sample showed that the values of these domains of quality of life were much lower, so the average value of vitality of our respondents was 44.95%, mental health 47.93%, general health 46.88%, physical functioning 47.10%, limitations due to emotional problems 52.66% and social functioning 48.92%. Although our results show lower values compared to the study by Lim et al.15, the reason for this is that their sample is from the general population, while our subjects had diseases for which they were exposed to long-term health care, so it can be expected that their quality of life will be lower compared to the general population.

In the study by Čanković et al.16 conducted in Serbia on a random sample of 200 people aged over 60 living in the Gerontological Center in Novi Sad, which is methodologically more similar to our study, the quality of life was assessed from the aspect of physical, psychological and social status. To assess the quality of life, the WHO questionnaire on the quality of life - short version (The World Health Organization Quality of Life BREF questionnaire, WHOQOL-BREF) was used. The authors determined that 137 (68.8%) respondents have a chronic disease, and that physical health was significantly worse in people with chronic diseases compared to people without chronic diseases (61.8% vs. 76.4%, p =0.001), mental health also (62.2% vs. 71.5%, p=0.002), while no difference was observed in social functioning16.

In our research, we showed that 72% of the respondents had a chronic disease, and that this group of users of long-term health care had a significantly lower level of physical functioning compared to the group of respondents without chronic diseases, while we did not observe a difference in the domains and summary score of mental health. However, our respondents who received long-term health care institutionally had significantly more chronic diseases (82%) compared to respondents who received long-term health care outside the institution (62%) (p=0.026). Čankovićet al.16 did not find that older age significantly affects the change in the physical or mental component of quality of life, which agrees with our results, in which we did not observe that the older age group had significantly lower values of domains and summary score of quality of life. In addition to chronic diseases, which we determined affect the physical functioning of our respondents, we also determined that satisfaction with monthly financial income has a significant impact on the quality of life of users of longterm health care. Our results showed that respondents who were satisfied with their monthly financial income (43%) had a significantly higher average value of the domains of physical functioning (p=0.038) and social functioning (p=0.021), compared to respondents who were not satisfied with their monthly financial income. incomes. While the difference in average values of other domains and summary scores between groups of long-term health care users divided according to satisfaction with financial income was not observed. Our results are confirmed by the study of Egeljić-Mihajlović et al.10 who, in their research conducted in the Republic of Srpska on a sample of 159 elderly respondents, showed that a poorer financial status significantly affects the quality of life of the elderly, as well as a poorer educational status, whereby respondents with a higher education had a significantly better health, social and financial status compared to older people with a lower level of education 10.

Research in Croatia shows that around 60% of elderly people who are housed in nursing homes are satisfied with their lives, while 12.8% are dissatisfied. The authors state that the level of life satisfaction among elderly people who live outside institutions is significantly better. Also, about 30% of institutionalized elderly people assessed their satisfaction with life as mediocre, and the variables of satisfaction with participation in activities at home, the variety of contents offered and satisfaction with the frequency of social events had the lowest value13. A study of aging conducted in Ghana concluded that older people are very concerned about self-care, mobility and normal activities of daily living17. The study suggests that there should be a public health policy that addresses the satisfaction and quality of life of the elderly.

Although there is a lot of data in the literature about the quality of life of elderly people, they should be separated from our research, because our population of respondents, although older, is not healthy and our sample is not from the general population, but from the population of people who have health problems and program is long-term health care.

In conclusion, we can state that users of long-term health care placed in an institution had significantly worse physical functioning, a higher level of limitations due to physical problems, worse general health, a lower level of social functioning and mental health, as well as a greater presence of chronic diseases.

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