# **Original Article**

# Quality of Life and Psychosocial Functioning in Greek Children with Cancer

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#### Abstract

**Background**: Children with cancer face many challenges and commonly develop somatic, emotional and behavioral symptoms that negatively affect their quality of life (QoL) and their psychosocial functioning.

Aim: The aim of this study was to assess the QoL of children with cancer and to address their emotional and behavioral symptoms.

**Methodology**: This is a non-invasive descriptive study. We assessed children's QoL using proxy reports from one of their parents, in a sample of 100 children with cancer, during their hospitalization in one of the two major pediatric public hospitals in Greece. The proxy form of "Quality of Life Scale" (QoLS) was used to assess QoL and the PSC-35 scale for the reporting of their children's emotional and behavioral symptoms, as reported by their parents. Data analysis was performed using Statistical Package SPSS version 23.0 (SPSS, Inc., Chicago, IL).The significance level was set at 0.05.

**Results**: The study participated 100 parents (24 fathers, 76 mothers) with a mean age of  $41.94 \pm 5.27$  years. Their children (51 boys, 49 girls) with a mean age of  $10.74 \pm 4.21$  years were hospitalized during the interviews in an oncology unit. Parents reported a quite high overall score in QoLS (Mean  $\pm$  SD: 97.85  $\pm$  22.84, Median: 94, IQR: 52-

151) indicating that their children experience an overall acceptable quality of life. Moreover, mothers rated higher QoL of their children than fathers in the Social Dimension and the subscales of Communication Ability and Self-assessment. The PSC-35 scale was used to assess the psychosocial dysfunction of the children (attention, externalizing, and internalizing symptoms) as rated by their parents. The mean score was lower than the cut off level (Mean  $\pm$  SD: 18.01  $\pm$  6.78) and only 12% of the participants states scores >24, indicating dysfunction. However, despite the PSC-35 score, the 25% of parents believe that their child has emotional or behavioral problems and 84.1% of them expressed their will for psychological support for their child.

**Conclusions**: The QoL in Greek children with cancer is rated as high according to their parents' reports. However, a number of them are dealing with emotional or behavioral symptoms that require experts' support.

Keywords: Pediatric nursing, Oncology nursing, Quality of life, Behavioral Symptoms

#### Introduction

Pediatric cancer treatment is a great success story, with continuously increasing cure rates but there are still major consequences, such as complications, disabilities, or adverse outcomes as a result of the disease process, the treatment, or both, may have a negative impact on daily functioning and quality of life of the child and consequently and to the other family members (Kaya et al., 2019).

Promoting quality of life (QoL) in children with cancer is a core challenge for pediatric nurses. It is a fact that these children experience a variety of physical, emotional, psychological, social and even spiritual symptoms that have a negative impact on both themselves and their family (Vlachioti et al., 2016; Rosenberg et al., 2016; Abu-Saad Huijer, Sagherian & Tamim, 2013). The most commonly reported symptoms are feelings of irritability, nervousness, lack of energy, lack of appetite, pain and sadness while the most common treated symptoms were nausea, vomiting, cough and pain with success rates ranging between 56.3 to 73.7% (Abu-Saad Huijer, Sagherian & Tamim, 2013). In literature there is a number of recent studies that assessed QoL in children with cancer using selfreports. However, their results were not consistent. For example, Calaminus et al. (2000) reported that children with cancer self-rated their overall QoL as good during the treatment. More recent studies also confirm these findings assessing QoL in children with cancer as good or relatively good (especially on cognitive performance, communication and nausea) (Hegazy et al., 2019; Abu-Saad Huijer, Sagherian & Tamim, 2013). However, there is a number of studies used self-reports that found no difference in QoL during treatment, but there was a noticed improvement at the end of treatment (Vlachioti et al., 2016), or even rated QoL as rather poor (especially the physical and school dimension compared to emotional and social dimension) (Rosenberg et al., 2016).

On the other hand there is a number of studies that used parental reports (proxy) to assess children's QoL. These studies were based in the belief that the views of parents reflect with relative certainty the views of children (Germain, Aballéa & Toumi, 2019; Batalha, Fernandes & Campos, 2015). Several studies expressing the views of parents have focused on investigating the QoL of children hospitalized at various stages of cancer treatment (Almomani, 2015) as well as in childhood cancer survivors (Calaminus et al., 2021). However, it seems that the QoL of children with cancer is related to a number of factors and its further investigation is necessary (Hegazy et al., 2019).

In addition, few studies have focused on investigating the QoL of children with cancer in Greece (Vlachioti et al., 2016). According to the literature, among the factors that negatively affect the QoL of children with cancer is the simultaneous treatment of cancer, the intensity of treatment (Almomani, 2015), duration of treatment and diagnosis (Hegazy et al., 2019), type of cancer (Calaminus et al., 2000; Almomani, 2015), poor prognosis or recurrence, older age and gender (Calaminus et al., 2000; Hegazy et al., 2019). There is evidence that education, communication and exercise have a positive effect on the QoL of children with cancer (Akdeniz Kudubes et al., 2022).

The effect of physical symptoms on the children's with cancer QoL has been studied (Hegazy et al., 2019; Stenmarker et al., 2018; Abu-Saad Huijer,

Sagherian & Tamim, 2013), however less evidence exists in relation to the psychosocial functioning and its effect on QoL (Vlachioti et al., 2016). The aim of this study was to assess the QoL of children with cancer and to address their emotional and behavioral symptoms, through their parent's reports.

# Materials and Methods – Study design

This is a non-invasive descriptive study. One of the parents of patients aged 5-18 years with a diagnosis of cancer who were treated in an oncology ward in one of the two biggest public pediatric hospitals in Greece ("Aghia Sophia" and "P. & A. Kyriakou"), during the study period (May to August 2021) and met the criteria for inclusion in the study, was recruited (sample of convenience). The 89% of the parents that were asked to participate agreed to participate and filled out the research form after informed consent was granted. This study was approved by the Research Ethics Committees of both Public Hospitals (Ref. No: 9343/18.05.2021 and Ref. No: 1568/27.01.2021).

The inclusion criteria for the parents in order to participate the study were: parenting a child 5-18 years old with neoplastic disease who was hospitalized in the oncology department during the study period, good knowledge of the Greek language and signed informed consent. We excluded three parents due to partial completion of the scale.

For the data collection, a special query form was developed which included a demographic form, the "Pediatric Symptom Checklist (PSC-35)" (Jellinek, Murphy & Burns, 1986) and the "Quality of Life Scale (QoLS)" (Wang et al., 2018). The PSC-35 scale consists of 35 questions and assesses a wide range of emotional and behavioral symptoms in children and was originally designed as a brief screening tool to assess general psychosocial dysfunction in children. Scale items were rated by participants on a 3-point Likert scale from 0 (never), 1 (sometimes) and 2 (often). The tool is scored by adding these scores together. It is applicable for use with children between the ages of 4 and 18 and usually takes less than five minutes to administer.

The QoLS explores the QoL of children with cancer, it is consisted by 35 questions covering five dimensions (Physiological (11 items), Psychological (7 items), Social (6 items),

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Environment (9 items), School role (2 items)). Each item is rated with a 5-point Likert scale from 1 (not at all significant) to 5 (very significant).

**Validation of scales:** Both scales were translated into Greek and evaluated by 2 experts for their adaptation to Greek culture. Then there was a reverse translation from Greek into English. As long as there was no discrepancy between the Greek and English translations the scales were accepted for use. After the scales were accepted, a pilot test was performed on 30 patients and one of their parents to check their reliability and validity for use in the study. The reliability of the scales was checked by calculating the Cronbach's alpha index.

The Cronbach's alpha internal consistency coefficient for the PSC-35 scale (N = 35) was 0.789, indicating a high internal consistency of the scale. The Cronbach's alpha internal consistency factor for all QoLS questions (N = 35) was 0.915, indicating excellent internal consistency of the scale. In more detail, Cronbach's alpha consistency factor for individual QoLS scores is shown in Table 1.

Statistical analysis: The analysis of the data was performed with the statistical package SPSS v.23.0 and at a level of statistical significance 0.05. Appropriate descriptive techniques were used for data analysis. Descriptive techniques included the assessment of frequency, Mean and Standard Deviation (SE), Median and Intra-Ouadratic Range (IQR) for continuous variables and the frequency and percentage ratio for categorical variables. Kolmogorov-Smirnov test was used for quantitative variables. Parametric and non-parametric methods of analysis were used for inductive statistical analysis and related hypothesis control depending on whether the variables follow a normal distribution or not. More specifically, the  $x^2$  (chisquare test) was used to investigate the relationship between two categorical variables. Student's t-test was used to investigate the relationship between a quantitative variable following the normal distribution and a binary variable.

Results

The study involved 24 fathers & 76 mothers of a total of 100 children (51 boys, 49 girls) diagnosed with cancer, with a mean age of  $41.94 \pm 5.27$  years for parents and  $10.74 \pm 4.21$  years for children. Participant's detailed demographic data are presented in Table 2.

The mean age of the male participants (fathers N = 24) was  $42.58 \pm 5.22$  years (35-55 years) and  $41.74 \pm 5.31$  years (30-55 years) for the female participants (mothers N = 76). The mean age of the children was  $11.41 \pm 4.11$  years (5-21 years) for boys and  $10.04 \pm 3.42$  years (1-16 years) for girls.

Table 3 shows the mean values, standard deviations, median values and IQR for each QoLS subscale score and for its overall score. Parents report a high overall score on QoLS (Mean  $\pm$  SD: 97.85  $\pm$  22.84, Median: 94, IQR: 52-151) while reporting a high score on the Environmental Dimension (Mean  $\pm$  SD: 38.14  $\pm$  4, 46, Median: 39, IQR: 25-45) and in the Physical Dimension (Mean  $\pm$  SD: 28.20  $\pm$  11.32, Median: 27, IQR: 11-52).

The variation of the overall QoLS score, its individual dimensions and subscales according to the gender of the parents was studied. The result of the test (t-test for independent samples) showed that there were no statistically significant differences between fathers and mothers except for the scores for the Social Dimension and the subscales for Communication Ability and Self-assessment, as shown in Table. 4. Specifically, mothers rated the QoL of their children higher than fathers and especially the Social Dimension and the subscales of Communication Ability and Self-assessment of QoLS (Table 4).

In addition, the effect of the child's age on QoL was investigated. The statistically significant differences are shown in Table 5. Specifically in specific dimensions / subscales of QoLS better QoL was reported in children <10 years old compared to children  $\ge 10$  years old (Table 5).

The mean PSC-35 score was lower than the cut off level (Mean  $\pm$  SD: 18.01  $\pm$  6.78) and only 12% of the participants states scores >24, indicating dysfunction. However, despite the PSC-35 score, the 25% of parents believe that their child has emotional or behavioral problems and 84.1% of them expressed their will for psychological support for their child.

The gender of the parent (p = 0.284) was not statistically significantly associated with the occurrence of pathological scores, although a statistically significant difference was found in the evaluation of parents by gender (t = -2,265, df = 98, p = 0.012), with mothers showing higher score (Mean  $\pm$  SD: 18.96  $\pm$  6.76) than fathers (Mean  $\pm$  SD: 15.00  $\pm$  6.01).

Our analysis revealed that the gender of the child did not differentiate the PSC-35 score (p = 0.230). Accordingly, neither the age of the parents nor the children was found to be related to PSC-35 score (p=0.232 & p=0.229, respectively). In contrast, parents' educational level was associated with abnormal scores, with parents with lower levels of education reporting higher PSC-35 scores for their children ( $x^2 = 12,142$ , df = 5, p = 0.033). Finally, hospitality and type of clinical care were not statistically significantly correlated with the PSC-35 rating.

Subscales	Cronbach's alpha		
	0.890		
Activity Ability Subscale (2 items)	0.785		
Somatic Function Subscale (4 items)	0.708		
Symptoms & side effects (5 items)	0.849		
	0.789		
Emotional Response (4 items)	0.780		
Self-evaluation (3 items)	0.776		
	Activity Ability Subscale (2 items) Somatic Function Subscale (4 items) Symptoms & side effects (5 items) Emotional Response (4 items)		

Table 1. Cronbach's alpha consistency factors for individual QoLS scores

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Social (6 items)		0.704
	Communication ability (2 items)	0.732
	Interpersonal relationship (4 items)	0.777
Environment (9 items)		0.651
	Home (5 items)	0.706
	Social (4 items)	0.705
School role (2 items)	Independence (2 items)	0.896
QoLS (35 items)		0.915

# Table 2. Demographic characteristics

Demographic characteristics	Frequency
Gender of parents	
Men	24
Women	76
Gender of child	
Boy	51
Girl	49
Age of parents	
$\leq 40$ years	42
>40 years	58
Age of child	
≤10 years	51
>10 years	49
Educational level	
High school graduate (3-years)	1
High school graduate (6-years)	20
Graduate of 2-year / 3-year post-secondary education cycle	16
Graduate of Higher Education	41
Holder of a Master's degree	19
Holder of a Doctoral Diploma	3
Hospital	
Α	37
В	63
Department	
Pediatric oncology	56

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Pediatric (other)

44
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# Table 3. QoLS score

		Mean ± SD	Median (IQR)
Physiological (11 items)		$28.20 \pm 11.32$	27 (11-52)
	Activity Ability Subscale (2 items)	$5.44 \pm 2.63$	5.50 (2-10)
	Somatic Function Subscale (4 items)	$10.41 \pm 4.48$	10 (4-20)
	Symptoms & side effects (5 items)	$12.35\pm5.83$	12.50 (5-25)
Psychological (7 items)		$19.43\pm6.77$	20 (7-33)
	Emotional Response (4 items)	$11.34 \pm 4.76$	12 (4-20)
	Self-evaluation (3 items)	$8.09\pm3.37$	9 (3-15)
Social (6 items)		14.45 ± 5.45	14 (6-28)
	Communication ability (2 items)	$6.34 \pm 2.74$	6 (2-10)
	Interpersonal relationship (4 items)	$8.07 \pm 4.25$	7 (4-19)
Environment (9 items)		38.14 ± 4.46	39 (25-45)
	Home (5 items)	$21.41 \pm 2.47$	21 (14-25)
	Social (4 items)	$16.73\pm3.17$	17.50 (8-20)
School role	Independence (2 items)	$3.92 \pm 2,78$	2 (2-10)
Total score (35 items)		97.85 ± 22.84	94 (52-151)

Table 4. Dimensions and subscales of QoLS with statistically significant variation with respect to parental gender

	Gender	Ν	$Mean \pm SD$	SE	t	р
<b>Dimensions / subscales</b>				Mean		
Social (6 items)	Man	24	$12.54\pm5.964$	1.217	-1.997	0.049
	Woman	76	$15.05\pm5.174$	0.594		
Communication ability (2	Man	24	$4.92\pm2.376$	0.485	-2.817	0.002
items)	Woman	76	$6.84 \pm 2.689$	0.308		
Self-evaluation (3 items)	Man	24	$6.46\pm3.257$	0.665	-3.140	0.006
	Woman	76	$8.41 \pm 3.254$	0.373		

Table 5. Dimensions and subscales of QoLS with statistically significant variation in relation to the age of the child

Dimensions / subscales	Age (years)	Ν	$Mean \pm SD$	SE Mean	t	р
Self-evaluation (3 items)	≥10	51	$7.41 \pm 3.176$	0.662	-1.384	0.039
	<10	49	$8.80 \pm 3.446$	0.663		

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Communication	ability	(2 ≥10	51	$5.71 \pm 2.928$	0.532	-1.376	0,011
items)		<10	49	$7/08 \pm 2.344$	0,529		
Social (6 items)		≥10	51	$15.94\pm3,\!397$	0,615	-1.610	0.010
		<10	49	$17,55 \pm 2,693$	0,612		

# Qualitative data

Parents stated a number of parameters that affect the quality of care their children receive and influence their experience. They report, for example, that a significant number of examinations are performed in different wards of the two hospitals rather than in a specific area for oncology wards. This, according their statements. "exposes" their to immunocompromised children to a risk of infection. Moreover, children who experience a change in self-image, due to the effects of the disease and/or treatment, may feel discomfort or exposed to "indiscreet eyes".

Another parameter that affects their hospitalization experience is that the information regarding the time and content of the examinations that their child will undergo is limited or takes place shortly before the actual performance of the test. According to parental statements, the children in the hospital have a limited number of activities during hospitalization and face many limitations, even regarding their nutrition. More specifically, it was reported that children have limited options regarding their diet as "... hospital food is standardized and does not provide options ...". While another parent characteristically stated "... it would be very nice if there was a restaurant and the children had the opportunity to choose food, breakfast and dinner ...". The limitations that children experience during their frequent hospitalizations and long treatment periods, seem to be important factors influencing their QoL. Characteristically, one parent stated "... While there is a playground, it is a pity that for long periods of time the child cannot take an outdoor walk while being treated ...".

An important parameter of the holistic care of the child as it is reflected by the parents, concerns the family-centered approach and the psycho-emotional support that is summarized in the following characteristic phrase "... my answers concern my child who is in the 4th year from the diagnosis of

Myeloid Leukemia .... we have gone through many stages ... but what I end up with is the essential psychological support of the children and the parents after the completion of the treatments ... there are many issues from all points of view ...".

The experience of pain seems to be of great concern for parents and was reported as the main determinant of their children's quality of life. One parent stated: "Often, a member of the nursing staff, due to lack of time, provides care to the children under pressure, in a way that it seems that doesn't care for the pain that causes them (for example, ... rubs the irritated skin with force in the gauze change to finish faster .... while with more time and patience it would cause less pain to the child ...".

# Discussion

The parents in our study assessed their children QoL as relatively good or very good, especially in relation to their physical state or interaction with their environment. However, pain, regular hospitalizations and activities limitations seem to be the main determinants of their QoL. At the same time, a limited number of children seem to develop psychosocial dysfunction based on PSC-35 scoring. Mandrell et al. (2016) in a similar study with parents caring for their children with cancer, found that children's QoL improves over time. For example, during the first month after starting cancer treatment the QoL is decreased but it is improved from 1<sup>st</sup> to 3<sup>rd</sup> month of treatment (Mandrell et al., 2016). However, Kalaycı & Çalışkan (2021) in a recent study with children with cancer reported low levels of QoL related mainly to socioeconomic factors and lack of support for children and their families (Kalaycı & Çalışkan, 2021). Ensuring nurses continue family-centered care during these processes are recommended to support the families. In another study in children with cancer, doctors and nurses reported that concept of OoL is important even in children at end of life and issues regarding palliative care must be addressed (Nagoya, Miyashita & Shiwaku, 2017).

The proxy evaluation of QoL in comparison to patient's perspective is challenging, mainly because QoL is a subjective outcome. Characteristically, Russell et al. (2006) concluded that parents of children with cancer receiving treatment underestimate the QoL of their children compared to that reported by the children themselves (Russell et al., 2006). It has been argued by other researchers that parents overestimated the health-related OoL of children with cancer compared to self-reported children (Bansal et al., 2014). It is generally argued that educating children about this assessment should precede parental assessment of the symptoms (Montgomery et al., 2021).

It was obvious from the qualitative and quantitative data analysis in our study that pain management and participation activities are in important determinants of QoL. Especially for children, playing and learning are an important part of a child's life. Playing is not only a distraction technique for children but rather a pragmatic need that must not be interrupted, even in cases of a lifethreatening illness such as cancer. Activities during hospitalization could be beneficial since they enhance and make more pleasurable the experience impacting children's QoL (Nagoya, Miyashita & Shiwaku, 2017). The need for better psychological support for children and better management of pain is in line with the findings of a study that emphasizes that 69% of all respondents experienced situations that indicate severe depression. In the same study the most common physical problem reported by children was pain (58%) and the most dominant areas of life that had a negative impact were body image (85%) (Lewandowska et al., 2021). In our study the parents of the children stated clearly that pain management affects the QoL of their child and the overall experience of hospitalization. Better pain management, especially regarding painful procedures and nursing interventions were argued by parents in our study. Parents also stressed the needs of children during hospitalization that affect their QoL. For example, the nutrition is an important factor. The fact that children are not able to choose their meals was stated to have a negative impact. The need for a tolerable and adequate child nutrition as stated from parents is in line with recent evidence indicating that most children did not consume adequate intake of vegetables (94% of patients), fruits (77%) and milk / alternatives (75%). Almost half (49%) of the children exceeded the recommendations for total sugar intake and 65% of the patients had excessive sodium intake (Cohen et al., 2021). Also 96% of the children had  $\geq$ 1 micronutrient deficiency and 39% had  $\geq$ 3. Eighty six percent of children were deficient in vitamin C, 87% were deficient in 25-hydroxyvitamin D, 50% were deficient in zinc and 13% were deficient in vitamin A (Morrell et al., 2019). Therefore, it is of great importance to provide a nutrition to children that will be favorable and the same time act as an important component of their care.

In literature there is a wide argument regarding the different needs of children, parents and family in total during the different phases of care from diagnosis to cure. Children with cancer in all phases of treatment have different nursing needs and their parents experience different levels of uncertainty that affect the QoL of parents and children (Park, Suh & Yu, 2021). Moreover, somatic and psychosocial symptoms have a significant effect on a child's QoL, interrelated to the illness severity and type of cancer (Cheung et al., 2019; Rodgers et al., 2019).

The mothers in our study rated higher QoL of their children in comparison to the fathers and especially in the Social Dimension and the subscales of Communication Ability and Self-assessment of QoLS. Gender differences regarding OoL assessment are widely stated in literature. Mothers' reports are commonly higher than fathers, and higher than their children in studies that we compare proxy with self-reports. However, socioeconomic parameters may alternate gender effect, for example Zheng et al. (2022) reported that mothers' low educational level has is associated with decreased QoL (Zheng et al., 2022).

Specific dimensions / subscales of QoLS have been reported to improve QoL in children <10 years of age compared to children  $\geq$ 10 years of age. Younger children had more stress and worse health related QoL. However, older children at the time of diagnosis were more concerned about the future and reported worse health related QoL (Zheng et al., 2022). However, another study states that the gender and age of children with cancer affect the reporting of emotional and psychological symptoms (Li et al., 2020).

More than one in ten children with cancer in our study were assessed by their parents using the PSC-35 scale to have a psychosocial dysfunction related to the physical symptoms from illness or/and treatment. Moreover, one in four parents stated that their child is in danger of a psycho-emotional disorder or behavioral problems and needs psychological support. In addition, mothers reported higher rates of psycho-emotional disorders or behavioral problems than fathers. Parents of children with cancer have claimed in a recent study that children experience a variety of physical, emotional and psychological disorders (Zheng et al., 2022; Montgomery et al., 2021; Li et al., 2020).

In our study parents' educational level was associated with the PSC-35 score, with parents with higher levels of education reporting higher PSC-35 scores for their children. As discussed earlier, Zheng et al. (2022) found that mothers with lower educational attainment reported more physical, emotional and psychological symptoms for their children with cancer while at the same time reporting worse QoL of these children, compared to mothers with higher educational level (Zheng et al., 2022). Level of parental and child information and family centered care are key aspects that influence the experience of care for both parents and their children. Especially the need for better information among adolescents with cancer is illustrated in recent studies (Sisk et al., 2022; Hancock et al., 2022).

The present study has a number of limitations. We used a convenience sample from the two major public pediatric hospitals in Greece, however, to obtain a more comprehensive data, it is suggested that children and their parents in private hospitals should be included in future. Moreover, the study was implemented for a short period and was conducted during the outbreak of the COVID-19 pandemic that affected children's QoL also. Moreover, self- reports in addition to parental reports may be useful to have a wider view regarding QoL and its determinants in children with cancer. On the other hand, our findings have some important implications for practice. Despite the high QoL reported by parents of children with cancer, children show many emotional and behavioral

problems and more emphasis should be placed on their psychological support.

**Conclusions:** This study emphasizes on the need for increase QoL of children with cancer and good psychosocial functioning. Parents reported an overall high QoL for their children with cancer and an overall good psychosocial functioning. However, one in four parents reported that their child has emotional or behavioral problems and there is a need psychological support of their children. for Noticeably, parents' gender and education may affect their symptom report. Pain management and in hospital activities have a direct impact on QoL and experience of hospitalization, especially among older children and teenagers. This study is a basis for further research into the OoL of children with cancer in Greece and the assessment of their emotional and behavioral symptoms.

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