



## VALIDATION OF THE ROMANIAN VERSION OF THE SCALE FOR QUALITY OF LIFE FOR YOUNG PEOPLE WITH CANCER

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### *Abstract*

*Through this study we want to see what are the indicators that affect the quality of life of young cancer survivors and the validation of the scale of evaluation of the quality of life of young people with cancer, 18-25 years, PedsQL (Varni, Seid, Rode, 1999) in the population of our country. To evaluate the quality of life, a specific evaluation tool was used, namely PedsQL (Varni, Seid, Rode, 1999) with 27 items (2 items for pain, 5 items for nausea, 3 items for anxiety in procedures, 3 items for anxiety in treatment, 3 items for concern, 3 items for anxiety, 5 items for cognitive problems, 3 items for physical perception, 3 items for communication) and Hospital Anxiety Depression Scale (HADS), (Ladea, 2003) with 14 items and two subscales, one for anxiety (7 items) and one for depression (7 items). The study demonstrates the validity of the PedsQL (Varni, Seid, Rode, 1999) scale for patients participating in the study, and the results of the study provide indicators to specialists involved that can improve their daily work, communication with patients and possibly a better quality of life for the young cancer patient and for all involved in the care of a young survivor*

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**Keywords:** *young, cancer, quality of life, survivor*

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### 1. INTRODUCTION

Adolescents and young adults (AYA) with cancer are experiencing multiple symptoms as a result of the disease and treatment. Accurate symptom assessment is vital for high quality supportive care and therapy evaluation. Research addressing symptoms among individuals with cancer has increased in the past 20 years, but nonetheless, symptom research among AYA as a distinct population is limited. Diversity among the AYA age group in terms of development and life experiences

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in general creates challenges in designing studies as well as identifying the evaluation of appropriate symptoms. AYA 18 years of age are most commonly treated at pediatric centers and included in study samples with younger children, and AYA over 18 years are included in studies with adults. This division of AYA into research prevented progress in identifying the symptoms that address this target group (Linder et al., 2015). Validated tools for measuring symptoms across the entire AYA age range (between 15 and 39 years) are rare, and in our country there is no validated quality of life tool for adolescents/young people with cancer.

Psychosocial problems of adolescents/young people with cancer are: changes in the perception of the physical/bodily image when self-confidence is so important for AYA, self-respect and social integration, mutilating / disfigurement surgery, acne, weight gain or weight loss, infertility, delay of puberty, interruption of normal sexual function, loss of independence, discontinuation of education or employment, family conflicts, isolation of siblings ("stigma" of cancer), struggle to reconcile with diagnosis, keeping hope (Mountzios, 2019). It is important to measure the quality of life in adolescent/young patients with cancer, namely personal relationships, sexuality, employment, financial problems, education, emotions, body image and self-esteem.

Psychosocial support and palliative care are also important components of cancer care. Long-term supervision should include both the physical and the psychological side because pediatric cancer survivors face difficulties in restoring their lives at school, at home and at community level (Fitzpatrick, 2016).

## **2. OBJECTIVE AND HYPOTHESES**

### **2.1. OBJECTIVE**

Through this study we want to see what are the indicators that affect the quality of life of young cancer survivors and validation of the scale of evaluation of the quality of life of young people with cancer 18-25 years, PedsQL (Varni, Seid, Rode, 1999) in the population of our country.

### **2.2. HYPOTHESES**

The working hypothesis was that for young people with cancer survivors the level of quality of life in all the areas it encompasses is significantly affected by certain indicators.

## **3. METHOD**

To evaluate the quality of life of young people with cancer, PedsQL (Varni, Seid, Rode, 1999) was used with 27 items (2 items for pain, 5 items for nausea, 3 items for anxiety in procedures, 3 items for treatment anxiety, 3 items for concern, 3 items for problems, 5 items for problems cognitive, 3 items for perception on the physical aspect, 3 items for communication, each item has five variants reflecting

severity, rated from 0 to 4) and Hospital Anxiety Depression Scale (HADS) with 14 items validated on our population by Maria Ladea (2003). After the agreement was obtained to translate the life assessment scale for young people with cancer from the Mapi Research Trust, the translation was done by two Romanian translators authorized for English. The differences between the two translations were discussed, then a Romanian version was finalized. Another authorized translator translated this version into English and there were no understandable differences from the original English version. The test for the validation of the PedsQL scale (Varni, Seid, Rode, 1999) was done through a survey in July 2019 on a batch of 35 young people, 18 women and 17 men between the ages of 18 and 25 years ( $M = 20$  years + - 2 SD, 95% CI. )

Validity was performed by testing the concurrent validity between PedsQL scale (Varni, Seid, Rode, 1999) on the one hand and the HADS (Hospital Anxiety and Depression Scale) scale (Ladea, considered “golden standard”) on the other. The HADS scale is a two-dimensional 14-item scale that contains two subscales, one for anxiety (7 items) and one for depression (7 items). The HADS (Ladea, 2003) scale has been widespread over the past twenty years, is short and is for identifying anxiety and depressive states and the severity of these conditions. For the statistical analysis of the results obtained from the two tests, the statistical software Epi Info was used, a statistical software developed by the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia (USA) and licensed as a public domain.

The association between the response categories was analyzed using the chi-squared test, the contingency table between the items in the PedsQL (Varni, Seid, Rode, 1999) scale. Linear regression was used to identify which variables are, in particular, significant predictors of the outcome variable and to explain the relationship between a dependent variable and one or more independent variables. Regression analysis helps us to understand how much the dependent variable changes with a change in one or more independent variables, and in this analysis the following indicators are used: *Coefficient* - the regression coefficient that represents the average of the response variable change for a single unit of change in the predictor variable while keeping other predictors in the model constant; *Std error* - the standard error is an estimate of the standard deviation of a coefficient; *P-value* a predictor with a low p-value is a significant addition to the model because the variations of the predictor value are correlated with the changes of the response variable; *Constant*-guarantees that the residues do not have a positive or negative overall tendency and serve as a waste bin for any prejudice that is not explained by the terms in the model; *Correlation Coefficient*:  $r^2$ - expresses the intensity of the connection between the regression series, and  $r > 0$  indicates direct links and  $r$  close to +1 indicates a close link between variables; *Sum of Squares*- provides information on how long the estimated regression line is from the horizontal line

"no relationships"; *Mean Square*- provides information on the differences between samples; *F-statistic*- says if a group of variables are significant in common; *Residuals* - the difference between the observed value and the predicted value.

#### 4. RESULTS

For the fidelity of the PedsQL test (Varni, Seid, Rode, 1999), the internal consistency ( $\alpha$  Cronbach) was calculated in Excel, and the internal consistency for the Romanian version of the scale ( $\alpha$  Cronbach) has the value of 0.68, a value below 0.7 which indicates the need for retesting, possibly and a larger number of respondents.

A statistically significant association was established between the item *I worry about recurrence of the cancer* in the worry section of the PedsQL (Varni, Seid, Rode, 1999) scale with *I feel too bad in the stomach to eat* (table 1) and *I worry about whether or not my medical treatments on the same scale work* (table 2). (probability  $p < 0.05$ , chi-squared test, df-degrees of freedom).

The total responses from the two subscales of the HADS (Ladea, 2003) scale indicate the easy level for both the anxiety subscale and the depression subscale. The item with the highest score in the anxiety subscale is *I worry*, and the item with the highest score in the depression subscale is *I like it as much as I liked before*. The interaction between the dependent variable was analyzed *I like what I liked before* with the independent variables *I feel too bad in the stomach to eat* (table 3) and *I worry about whether or not my medical treatments work* (table 4) through the regression model and the result obtained is statistically significant  $p = 0.000$  ( $p < 0.05$ , F-test).

Table 1- Item association *I worry that the cancer will recur* with the item *I feel too bad in the stomach to eat*

	<i>I feel too bad in the stomach to eat</i>				
<i>I worry that the cancer will recur</i>	0	1	2	3	Total
<b>0</b>	1	0	0	1	2
Row%	50.00%	0.00%	0.00%	50.00%	100.00%
Col%	5.88%	0.00%	0.00%	50.00%	5.71%
<b>1</b>	3	5	1	1	10
Row%	30.00%	50.00%	10.00%	10.00%	100.00%

Col%	17.65%	45.45%	20.00%	50.00%	28.57%
<b>2</b>	12	4	1	0	17
Row%	70.59%	23.53%	5.88%	0.00%	100.00%
Col%	70.59%	36.36%	20.00%	0.00%	48.57%
<b>3</b>	1	2	3	0	6
Row%	16.67%	33.33%	50.00%	0.00%	100.00%
Col%	5.88%	18.18%	60.00%	0.00%	17.14%
<b>TOTAL</b>	17	11	5	2	35
Row%	48.57%	31.43%	14.29%	5.71%	100.00%
Col%	100.00%	100.00%	100.00%	100.00%	100.00%

Chi-Squared    df    Probability  
 20.8471    9    0.0133

Row% - Percentage of the total item *I am worried that the cancer will recur* for each response variant; Col% - percentage of the total item *I feel too bad in the stomach to eat* for each answer variant

Table 2- Item association *I worry that the cancer will recur* with the item *I worry about whether or not my medical treatments work*

	<i>I worry about whether or not my medical treatments work</i>				
<i>I worry that the cancer will recur</i>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>Total</b>
<b>0</b>	2	0	0	0	2
Row%	100.00%	0.00%	0.00%	0.00%	100.00%
Col%	28.57%	0.00%	0.00%	0.00%	5.71%
<b>1</b>	0	7	2	1	10
Row%	0.00%	70.00%	20.00%	10.00%	100.00%
Col%	0.00%	77.78%	13.33%	25.00%	28.57%

<b>2</b>	5	2	10	0	17
Row%	29.41%	11.76%	58.82%	0.00%	100.00%
Col%	71.43%	22.22%	66.67%	0.00%	48.57%
<b>3</b>	0	0	3	3	6
Row%	0.00%	0.00%	50.00%	50.00%	100.00%
Col%	0.00%	0.00%	20.00%	75.00%	17.14%
<b>TOTAL</b>	7	9	15	4	35
Row%	20.00%	25.71%	42.86%	11.43%	100.00%
Col%	100.00%	100.00%	100.00%	100.00%	100.00%

Chi-Squared df Probability  
34.4824 9 0.0001

Row% - Percentage of the total *item I am worried that the cancer will recur* for each response variant; Col% - percentage of the total *item I worry about whether or not my medical treatments work* for each answer variant

**Tabel 3- Linear Regression-** *item I feel too bad in the stomach to eat*

Variable	Coefficient	Std Error	F-test	P-Value
<i>I like it as much as I liked before</i>	0.235	0.109	4.6490	0.038457
<b>CONSTANT</b>	-0.031	0.253	0.0146	0.904405

**Correlation Coefficient:**  $r^2 = 0.12$

Source	df	Sum of Squares	Mean Square	F-statistic
<b>Regression</b>	1	1.080	1.080	4.649
<b>Residuals</b>	33	7.663	0.232	
<b>Total</b>	34	8.743		

**Tabel 4- Linear Regression- I worry about whether or not my medical treatments work**

Variable	Coefficient	Std Error	F-test	P-Value
<i>I like it as much as I liked before</i>	0.235	0.109	4.6490	0.038457
CONSTANT	-0.031	0.253	0.0146	0.904405

Correlation Coefficient:  $r^2 = 0.12$

Source	df	Sum of Squares	Mean Square	F-statistic
Regression	1	1.080	1.080	4.649
Residuals	33	7.663	0.232	
Total	34	8.743		

## 5. CONCLUSIONS

High fear of cancer recurrence (FCR) is a commonly reported problem in cancer patients. Previous research has shown that younger age is associated with higher levels of FCR. However, so far, little attention has been paid to how FCR manifests itself among adolescents and young adults (AYA) cancer patients. A 2018 study explores the prevalence, high FCR correlations and its association with HRQoL in cancer patients in adolescence or young adulthood. Seventy-three AYA cancer patients, aged between 18 and 35 years at diagnosis, consulted the AYA team at Radboud University Medical Center, completed questionnaires, including the Cancer Concern Scale, CWS, (Lerman, Trock, Rimer, Jepson, et al., 1991) Quality of Life of Survivors cancer, QOL-CS, (Ferrell, Hassey-Dow, Grant, 2012) and Anxiety and Depression Scale (HADS), (Ladea, 2003). The socio-demographic and medical data were collected through a self-reported questionnaire. Forty-five participants had a high level of FCR (62%), and high FCR was significantly associated with lower levels of social and psychological functioning and general HRQOL and higher levels of anxiety and psychological distress. The results illustrate that FCR is a significant problem among AYA cancer patients, with participants reporting higher levels of FCR than mixed-age cancer patients.

Healthcare providers should pay specific attention to this issue by screening and providing appropriate psychosocial care when needed (Thewes et al, 2018).

Quality of life, anxiety and depression among people diagnosed with adolescent cancer up to 4 years after diagnosis and compared to a reference group were investigated in a study in 2010. The cancer group (N = 61) completed a SF-36 mental health and vitality questionnaire, and anxiety and depression through HADS subscale (Ladea, 2003) shortly and at 6, 12, 18, 24, 36 and 48 months after diagnosis. The reference group (N = 300) randomly extracted from the civil register of the Swedish population of statistics completed the same tools for an evaluation. Data were collected through telephone interviews. Up to 6 months after diagnosis, the cancer group reports lower levels of mental health and vitality and a higher level of depression than the reference group. At 18 months after diagnosis a reverse condition occurs and at 48 months after diagnosis, the cancer group reports a higher level of vitality and a lower level of anxiety and depression than the reference group. The results suggest that a positive psychological change may occur following cancer during adolescence. However, efforts should be made to enable clinicians and healthcare personnel to identify and provide psychological support to people experiencing poor quality of life and high emotional distress. If these problems remain undetected and adequate support is not provided, suffering can become a barrier to physical recovery, leading to a vicious cycle of physical and mental disability (Larson et al. 2010).

Adolescents with cancer must cope with their disease and their treatment, while fulfilling the unique tasks of this developmental period. In a pilot study, the prevalence of psychological morbidity among adolescents with cancer was examined. In addition, the evaluation methods and risk factors were analyzed. Forty-three recently diagnosed with cancer completed the Anxiety and Depression Scale, HADS, (Ladea, 2003) Beck Depression Inventory, BDI, (Beck, Steer, Carbin, 1988) and Rotterdam Symptom Checklist, RSCL, (De Haes et al., 1983) and underwent a comprehensive psychiatric evaluation. In psychiatric interviews, 9% of the participants were diagnosed with a depressive disorder of disposition. The results suggest that self-report assessment scales may be useful assessment tools if used as complementary tools. However, psychosocial assessment of the adolescent with cancer is difficult. This seems to be due to an atypical symptoms model and a tendency to mask stress. Examining cases in patients with depression suggests that diseases and treatment factors may not be primary risk factors for the development of psychological morbidity. External stressors, such as poor family support and previous sexual abuse, when worsened by disease and treatment factors, may be more relevant (Berard, Boormeester, 1998).

The pediatric quality of life measurement model, PedsQL (Varni, Seid, Rode, 1999) was developed to assess the quality of life specific to health-related diseases (HRQOL) in child populations. Currently, there are no systematic reviews of the

studies that examined the psychometric properties of the generic PedsQL Baseline Scales in pediatric cancer patients and survivors (Varni, Seid, Rode, 1999). The 2016 study aimed to answer the question "What is the reliability, validity, feasibility, measurement range and responsiveness of PedsQL generic baseline scales (Varni, Seid, Rode, 1999) in pediatric cancer patients and survivors?" Between 2001 and February 2016, they were included in the review if they evaluated the reliability, validity, feasibility, measurement range and / or responsiveness of the PedsQL generic baseline scales in a pediatric oncology sample or a survivor sample. Two independent reviewers searched the PsycINFO and PubMed databases, which led to 16 studies that met the full inclusion criteria. The analyzed studies were published between 2002 and 2014 and were conducted in 12 different countries. Most studies reported Cronbach's alpha, which reached or exceeded 0.70 for the parent report and the child self-report for 8-18 years. Almost all studies evaluating construct validity concluded that cancer patients and their parents reported statistically significantly lower HRQOL than healthy children in the PedsQL (Varni, Seid, Rode, 1999) domains. Taken together, the studies in the study demonstrate acceptable psychometric properties of the generic PedsQL Baseline Scales (Varni, Seid, Rode, 1999) in pediatric cancer patients and survivors. Further validation studies are warranted to establish the reliability of the test and the reactivity over time of the generic PedsQL (Varni, Seid, Rode, 1999) baseline scales in this population (Cancer.net Editorial Board, 2018).

The word "survival" means different things to different people. Common definitions include: No signs of cancer after termination of treatment / Living with, through and beyond cancer. According to this definition, cancer survival begins with diagnosis and includes people who continue to have long-term treatment, either to reduce the risk of recurrence or to manage chronic diseases. Survival is one of the most complicated parts of cancer. This is because it is different for everyone. Survivors may experience a mixture of strong feelings, including joy, worry, relief, guilt, and fear. Some people say they value life more after a cancer diagnosis and have gained greater acceptance of them. Others become very impatient about their health and are uncertain about coping with daily life. Survivors may feel stress when their frequent visits to the healthcare team end after treatment is over. Often, the relationships built with the cancer care team provide a sense of security during treatment, and people miss this source of support. This can be especially true when new problems and challenges arise over time, such as any late effects of treatment, emotional challenges, including fear of recurrence, issues of sexuality and fertility, and financial and workplace problems. Each survivor has individual concerns and challenges. With any challenge, a good first step is to be able to recognize your fears and talk about them. Effective coping requires: Understanding the challenge you are facing / Thinking through solutions / Asking and supporting others. Many survivors find it helpful to join a personal support

group or online survivor community. This allows you to talk to people who have had similar experiences. Other options for finding help include discussing with a friend or a member of the healthcare team, individual counseling, or requesting assistance from where they received treatment (Limbers & Larson, 2016).

The study demonstrates the validity of the PedsQL (Varni, Seid, Rode, 1999) scale for the patients participating in the study, the results of the study offer specialists in the care team benchmarks to identify elements of anxiety and depression, benchmarks that can improve communication with patients and possibly a better quality of life for everyone involved in the study caring for a young patient with surviving cancer.

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