Original Research Article

Development of a scale for assessing the level of distress for children and adolescents with cancer

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Mihaela Camelia POPA¹

¹Institute of Philosophy and Psychology "Constantin Rădulescu - Motru", Romanian Academy, Romania.

Author E-mail:
beti_iris@yahoo.com

The present study aims to develop a short scale to assess the level of distress among children and adolescents with cancer. For the development of the scale 6 items were used which were highlighted by statistically significant associations from the research done in previous years under my coordination in which the quality of life assessment questionnaire for children and adolescents with cancer was used, the scale of irrationality for children and adolescents, the scale of post-traumatic development. The study included the 6 items and a specific 39-item stress assessment tool called the affective distress profile (PDA) that measures positive emotions, functional negative emotions, dysfunctional negative emotions. The results of the study obtained using factor analysis, internal consistency reliability and linear regression provide a short and effective tool for assessing stress among children and adolescents with cancer.

Keywords: Distress, cancer, depression, anxiety, quality of life

INTRODUCTION

Children and adolescents with cancer have a wide range of psychological problems such as: depressive symptoms, somatic, anxiety, low self-esteem, inability to cope inefficient, school, family, social or work problems. Thus, it seems that there are no optimal coping strategies, but different ways of approaching the situation, which may vary depending on specific circumstances and individual characteristics. The experience of having cancer can change the way children conceptualize problems so that they see fewer problems than before. It is also possible that children's adaptation is a consequence of the proper use of family coping strategies, as can be seen in some cancer survivors, who report emotional growth after illness, as well as feelings of happiness, well-being, hope, satisfaction, greater closeness to family, greater appreciation of aspects of life, more future prospects and a higher quality of life. (Muglia Wechsler et al., 2013).

A meta-analysis from 2021 highlights that anxiety symptoms have been experienced as some of the most severe and long-lasting by children and adolescents with cancer. Children and adolescents with cancer may not always be able to communicate their symptoms due to language difficulties or the severity of their illness (Mahakwe et al., 2021).

Interventions to increase feelings of control and regulate feelings of anxiety, such as mindfulness and cognitive-behavioral therapeutic approaches at the beginning of treatment can help alleviate long-term emotional stress (Yardeni et al., 2021).

There are currently two psychosocial screening tools available for children and adolescents with cancer, namely a person-oriented distress thermometer and a family-centered psychosocial screening tool for psychosocial risk. Stress is defined by a series of emotional reactions such as sadness, agitation, fear and worries experienced by the individual. Psychosocial risk has been defined as a combination of individual, family, social and economic factors that, when considered collectively, increase the likelihood that a family member or family may have difficulty managing and treating cancer challenges. (Barrera et al., 2014).

MATERIALS AND METHODS

The study was conducted in Bucharest, Romania in July 2021 through a survey and the number of respondents was 45 children and adolescents with cancer of which 22 girls

and 23 boys.

The working hypothesis of the study was that there is distress among children and adolescents with cancer and that there are statistically significant associations between items on the distress assessment scale and different emotions of affective distress.

The items that make up the short scale assessment of distress are: *I have a poorer school performance than last year / I have to force myself to do school activities / When it comes to starting to work on homework I think I need more time to have the necessary mood / I worry about my medical treatments / I worry about the side effects of my medical treatments / I worry about the pain in the needle prick (injections, tests, infusions, etc.)*

For the evaluation of distress, the affective distress profile (PDA) was used with 39 items grouped as follows: 6 items with functional negative emotions from the sadness category, 8 items with dysfunctional negative emotions from the depression category, 6 items with functional negative emotions from the anxiety category, 6 items with dysfunctional negative emotions from the anxiety category, 13 items with positive emotions. The PDA scale was designed for the Romanian population in 2005 by David Opreș and Bianca Macavei, and this scale is part of the clinical evaluation system (SEC) adapted in Romania by prof. univ. phd Daniel David.

For the statistical analysis of the results obtained from the two tests, the statistical program 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.

Linear regression was used to identify which variables are, in particular, significant predictors of the resulting variable and to explain the relationship between a dependent variable and one or more independent variables. Regression analysis helps us 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 change of the response variable 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 variations in the value of the predictor are correlated with changes in the response variable; *constant* - ensures that residues do not have an overall positive or negative trend and serve as a trash can for any bias that is not explained by the terms in the model; *correlation coefficient* - expresses the intensity of the connection between the regression series, and $r > 0$ indicates direct links, and r close to +1 indicates the close connection between the variables; *sum of squares* - provides information on how long the estimated regression line is from the "unrelated" horizontal line; *mean square* - provides information about the differences between the samples; *F-statistic* - shows whether a group of variables are significant in common; *residuals* - the difference between the observed value and the predicted value.

Main component analysis (PCA) was also used, an approach to factor analysis, which takes into account the

total variance of the data and turns the original variables into a smaller set of linear combinations. The task of the main component analysis is to identify the patterns in the data and to direct the data by highlighting their similarities and differences. In other words, PCA reduces the size of a multivariate data to two or three main components, which can be viewed graphically, with minimal information loss. (Balog et al., 2019).

RESULTS

The Likert ordinal psychometric scale was used for the distress assessment scale with the following response options: 1. Total disagreement / 2. Disagree / 3. Neither agree nor disagree / 4. Agree / 5. Strongly agree. The resulting distress level is an average level with a score of 17.6.

For the fidelity of the stress assessment scale, the internal consistency (α Cronbach) was calculated in Excel, and the internal consistency has the value of 0.7 result at the limit for the reliability of the internal consistency which indicates that the elements in the test are correlated with each other. a new study with a larger number of respondents.

Dimensions *I worry about the side effects of my medical treatments* and *I worry about my medical treatments* correlate most closely with the first component, and the size *I have to force myself to do school activities* correlates most closely with second component (Table 1, Figure 1).

The analysis of the emotional distress scale (PDA) shows an average level of distress among children and adolescents with cancer. (Table 2).

The interaction between the independent variable *Total dysfunctional negative emotions (depression)* and the dependent variables was analyzed. is statistically significant $p = 0.000$ ($p < 0.05$, F-test), Table 3.

The correlation coefficient indicated that 24% ($r = 0.49$) of the variable *Total dysfunctional negative emotions (depression)* can be explained by the variables *I have a poorer school performance than last year* and *I am worried about the pain of the needle prick*.

The interaction between the independent variable *Total functional negative emotions (sadness)* and the dependent variables was analyzed is statistically significant $p = 0.000$ ($p < 0.05$, F-test).Table 4.

The correlation coefficient indicated that 24% ($r = 0.49$) of the variable *Total functional negative emotions (sadness)* can be explained by the variables *I have a poorer school performance than last year* and *I worry about the pain of the needle prick*.

The interaction between the independent variable *Total dysfunctional negative emotions (anxiety)* and the dependent variables was analyzed is statistically significant $p = 0.000$ ($p < 0.05$, F-test).Table 5.

The correlation coefficient indicated that 24% ($r = 0.49$) of the variable *Total dysfunctional negative emotions (anxiety)* can be explained by the variables *I have a poorer school performance than last year* and *I am worried about the pain in the needle prick*.

The interaction between the independent variable *Total*

Tabel 1. Analysis of the main components

Component Loadings			
	RC 1	RC 2	Uniqueness
Worries_ stinging pain	0.776	.	0.443
Worries_ medical treatments	0.830	.	0.253
Worries_ side effects treatments	0.889	.	0.229
I need more time on homework	.	0.596	0.469
I force myself for school activities	.	0.803	0.406
Poor school performance	.	0.676	0.550

Note. Applied rotation method is promax.

Component Correlations		
	RC 1	RC 2
RC 1	1.000	
RC 2	0.320	1.000

Chi-squared Test			
	Value	df	p
Model	20.614	4	< .001

Figure 1: Analysis of the main components

Tabel 2. The total emotions of the emotional distress scale

	Positive emotions	Functional negative emotions (sadness)	Dysfunctional negative emotions (depression)	Functional negative emotions (concern)	Dysfunctional negative emotions (anxiety)	Total distress
children /adolescent	33.40	11.73	12.42	13.67	11.11	48.93

functional negative emotions (concern) and the dependent variables was analyzed is statistically significant $p = 0.000$ ($p < 0.05$, F-test).Table 6.

The correlation coefficient indicated that 24% ($r = 0.49$) of the variable *Total functional negative emotions (concern)* can be explained by the variables *I have a poorer school performance than last year* and *I am worried about the*

pain in the needle prick.

In the present study there was also an open item through which the respondents were asked to write a message for those who live a long experience in the hospital, and the messages were the following: "Children do not be sad, you will do well, you have hope, believe in this and it will be good!/ Have great confidence in what the doctors say and

Tabel 3. Linear regression - Total dysfunctional negative emotions (depression)

Variable	Coefficient	Std Error	F-test	P-Value
<i>I have a poorer school performance than last year</i>	0.171	0.066	6.6629	0.013426
<i>I am worried about the pain in the needle prick</i>	-0.147	0.051	8.3947	0.005955
CONSTANT	0.541	0.206	6.8970	0.011997

Correlation Coefficient: $r^2=0.24$

Source	df	Sum of Squares	Mean Square	F-statistic
Regression	2	2.713	1.356	6.677
Residuals	42	8.532	0.203	
Total	44	11.244		

Tabel 4. Linear regression - Total functional negative emotions (sadness)

Variable	Coefficient	Std Error	F-test	P-Value
<i>I have a poorer school performance than last year</i>	0.171	0.066	6.6629	0.013426
<i>I am worried about the pain in the needle prick</i>	-0.147	0.051	8.3947	0.005955
CONSTANT	0.541	0.206	6.8970	0.011997

Correlation Coefficient: $r^2=0.24$

Source	df	Sum of Squares	Mean Square	F-statistic
Regression	2	2.713	1.356	6.677
Residuals	42	8.532	0.203	
Total	44	11.244		

Tabel 5. Linear regression - Total dysfunctional negative emotions (anxiety)

Variable	Coefficient	Std Error	F-test	P-Value
<i>I have a poorer school performance than last year</i>	0.171	0.066	6.6629	0.013426
<i>I am worried about the pain in the needle prick</i>	-0.147	0.051	8.3947	0.005955
CONSTANT	0.541	0.206	6.8970	0.011997

Correlation Coefficient: $r^2=0.24$

Source	df	Sum of Squares	Mean Square	F-statistic
Regression	2	2.713	1.356	6.677
Residuals	42	8.532	0.203	
Total	44	11.244		

Tabel 6. Linear regression - Total functional negative emotions (concern)

Variable	Coefficient	Std Error	F-test	P-Value
<i>I have a poorer school performance than last year</i>	0.171	0.066	6.6629	0.013426
<i>I am worried about the pain in the needle prick</i>	-0.147	0.051	8.3947	0.005955
CONSTANT	0.541	0.206	6.8970	0.011997

Correlation Coefficient: $r^2=0.24$

Source	df	Sum of Squares	Mean Square	F-statistic
Regression	2	2.713	1.356	6.677
Residuals	42	8.532	0.203	
Total	44	11.244		

that you will become healthy in a short time, even if you no longer resist and fight hard!/ Never think about what is better/ Pray to God and hope for the time when they will be healed/ No matter the situation and how hard it would be

to get over it, there will always be hope that one day no matter how painful and long the situation will be there will always be a way in which everything will be fine even if everything will not be the same as before and we will lead a

slightly different life. We will always have to hope that everything will be fine and enjoy the remaining days as we have them. Maybe it's hard for us sometimes, but all that matters is that at some point we will be well and that we will be able to continue our life as it will be offered to us. Which you had to enter. Patience, trust in God and calmness are all three keys to success. I wish you good health and peace of mind! / Everything will be fine because no one receives a burden that he is not able to carry / In the end, everything will be fine / Forget about upset! / Think about everything you want to do outside the hospital and be strong in the face of treatment! / Laugh and be happy! No matter how long everything lasts, it will return to normal at some point and it won't last a lifetime and you will be able to return to the life you had before / Be optimistic, everything will be fine! / Be positive that you will come out from the hospital healthy and happy! / Have great trust in God, that He will help us to get along well everywhere! / I want all children to fight as I fought and I continue to fight to live a beautiful life with family. Good luck! / Be strong and trust in God! He will always be with you, for better or for worse! / Please do not lose hope, remember that time flies and that tomorrow, the day after tomorrow, you will be home with your family again! / Be strong and trust in God! / Medicine has advanced so much that almost anything is treated or a solution can be found for living. I know it's hard, I know you're still panicking, you're afraid of what's going to happen and possibly the needles from syringes, branules, etc.... everything will pass at some point, just think about it. Busy your mind with anything else, I guarantee it helps a lot. Don't be ashamed of yourself, with or without hair, you remain the same beautiful person who doesn't need anyone else's opinion. Keep in touch with friends, appreciate time with family and try to socialize as much as possible, to express everything you feel / I wish you much health, much hope and strength! Everything will be fine with God's help! / Be optimistic and always with a smile on your face! / Be very brave, trust first and foremost in the medical staff / Be strong, everything will pass! / You must be strong, optimistic and hopeful to attract the good. No matter how you feel, try to always find an activity to pass your time faster. The most important thing is to trust God and believe in Him and everything will be fine! / Trust God that you will be able to get over it! / You are strong and you can get over anything. It will be good! / Be strong and confident to overcome the disease / Be strong with the hope that everything will be OK! / Get up, go slightly to the mirror and smile! Look at the gleam on your face when you laugh! You are a wonderful and strong person! Fight and everything will be fine! Don't give up! / The moments in the hospital are painful and scary, but you have to keep thinking that this experience is only a short part of your life. You remain optimistic but you also have a little realism to realize and accept your current situation. And communicate as much as possible with your friends! / I will succeed! / Courage and hope are vital in this fierce war. Do not hesitate to use these weapons against evil! / As long as you hope, everything will be fine. / Take good care of them and think only of beautiful things, not negative ones, to occupy their time with something they like to do and be reassured that it will be fine no matter what the situation! / To believe

in them that they will succeed and to keep their heads up all the time and to believe in God!"

DISCUSSIONS

Children and adolescents with cancer often face complicated and burdensome treatments, which not only require a lot of time and energy to manage, but will also have an impact on relationships with parents, siblings and colleagues. Working with a psychologist can help alleviate these unique challenges and can have a positive impact on behaviors and health outcomes. (Rohan and Winter, 2021).

A 2017 study highlights that for adolescents with cancer there is a significant shortage and inequity in disease care across Europe and that management, dedicated clinical care, improved education and research focused on cancer care are a priority. (Saloustros et al., 2017).

According to a 2021 study, the concept of feeling unwell or well for children is determined by their ability to develop relationships with people, rather than being in the hospital for a medical problem. to be able to play, be active, and feel normal in a medical setting Children with cancer actively construct meaning for their sickness experience by mixing what is inside and outside of them: their individual experience as patients, the organisation of their social and cultural world, their sentiments, and those of their caregivers. as well as how the environment is structured and perceived Children do not simply play or seek for friends with whom to have fun. They pretend and interact with others in order to perform and feel alive. When hospitalised children encounter a rich and stimulating environment, they can make sense of reality, and their present and future perspectives become active and positive. Capurso and Renza (2002).

Daytime drowsiness, as reported by parents, affects about one-third of pediatric cancer survivors and is associated with poorer behavioral outcomes in the home and school environment and is therefore vital for sleep functioning to be an assessment target. annual survival care, and in the future longitudinal studies are required to further delineate the directionality of the sleep-neurobehavior relationship in survivors. (Oswald et al., 2021) Current findings suggest that the uncertainty of disease progression and dysfunctional problem-solving strategies can be managed through interventions that address psychological adjustment. (Basile et al., 2021).

One conclusion from a 2021 study is that there is a statistically significant positive correlation between the resilience of children with cancer and their quality of life, indicating that it is essential for health professionals to implement interventions to increase the resilience of children with cancer. their lives. (Chung et al., 2021)

There is a significant relationship between parents' psychosocial adjustment and the child's quality of life, and in the future parental stress is an important factor to assess in the context of pediatric cancer, as it seems to have implications for the child's quality of life, among other results. (Bakula et al., 2020).

A 2021 meta-analysis did not identify any studies specific to the management of anxiety and stress among children

and adolescents with cancer, and therefore clinicians lack guidance on how to manage these specific symptoms. Future research should provide specific recommendations for clinical evaluation and management of anxiety and stress in pediatric oncology (Lazor et al., 2021).

Conclusion

The results obtained in the study show that the short scale of assessment of the level of distress for children and adolescents with cancer, with *items I have a poorer school performance than last year / I have to force myself to do school activities / When it comes to starting to work on homework I think I need more time to have the necessary mood / I worry about my medical treatments / I worry about the side effects of my medical treatments / I worry about the pain at the needle prick (injections, tests, infusions, etc.)* effectively provides the psychologist working in the hospital or medical clinic with assessment and intervention guidelines during the acute period.

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