Quarterly Journal Fides et Ratio
Issue 1(53)2023, ISSN 2082-7067, Pages 62-68

Life Situation Scale for Parents of Children with Oncological Diseases – Polish adaptation

Skala Sytuacji Życiowej Rodziców Dzieci Chorych Onkologicznie – polska adaptacja[1]

https://doi.org/10.34766/fetr.v53i1.1172

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Abstract: *Introduction:* A child's cancer diagnosis causes severe stress for parents throughout the treatment process. Long-term stress, an uncertain prognosis and constant disposability cause the carers of a sick child to experience adverse changes in the areas of physical and psychosocial health. Their living situation depends on the support they receive from loved ones and from medical staff. Research on the assessment of their specific living situation is gaining importance, which requires the use of an appropriate tool. Such possibilities are provided by the Life Situation Scale for Parents of children with cancer. The article presents the next steps in the adaptation of this questionnaire. *Methods:* A total of 112 parents of children with cancer participated in the study. Parents were in the age range 25 to 59 years (M = 38.56 years; SD = 6.71). The procedure for adapting the Life Situation Scale for Parents (LSS-P) included verification of the factor structure and assessment of the psychometric properties of the Polish version of the questionnaire. *Results:* Statistical analyses confirmed the good psychometric properties of the Polish adaptation of the Life Situation Scale for Parents (LSS-P). The adaptation includes 20 statements and measures 3 types of support: social, emotional and institutional i.e. received directly from the medical staff. *Conclusion:* Life Situation Scale for Parents of children with cancer proved to be a valid and reliable tool. The scale can be used in diagnosing the needs of parents in the process of a child's cancer. This tool can be particularly useful in Oncology Departments, where it is important to care not only for the little patient, but also for their parents.
Keywords: child cancer, parental situation, psychometric evaluation, questionnaire.

Abstrakt: *Wstęp:* Diagnoza choroby nowotworowej u dziecka wywołuje silny stres, który towarzyszy rodzicom podczas całego procesu leczenia. Długotrwały stres, niepewne rokowania, nieustanna dyspozycyjność powodują, że opiekunowie chorego dziecka doświadczają niekorzystnych zmian w obszarach zdrowia fizycznego i psychospołecznego. Ich sytuacja życiowa zależy od wsparcia, jakie otrzymują nie tylko od osób bliskich, ale również od personelu medycznego. Znaczenia nabierają badania dotyczące oceny ich szczególnej sytuacji życiowej, co wymaga stosowania odpowiedniego narzędzia. Takie możliwości daje Skala Sytuacji Życiowej przeznaczona dla rodziców dzieci chorych onkologicznie (SSŻ). W artykule przedstawione zostały kolejne etapy adaptacji tego kwestionariusza. *Metoda:* Uczestnikami badania było 112 rodziców dzieci chorych onkologicznie. Rodzice byli w wieku od 25 do 59 lat (M = 38,56 lat; SD = 6,71). Procedura adaptacji The Life Situation Scale for Parents (LSS-P) obejmowała weryfikację struktury czynnikowej oraz ocenę właściwości psychometrycznych polskiej wersji skali. *Wyniki:* Analizy statystyczne potwierdziły dobre właściwości psychometryczne polskiej adaptacji Skali Sytuacji Życiowej Rodziców (SSŻ-R). Obejmuje ona 20 twierdzeń i mierzy 3 rodzaje wsparcia: społeczne, emocjonalne i instytucjonalne tj. otrzymywane bezpośrednio od personelu medycznego, *Wnioski:* Skala Sytuacji Życiowej Rodziców okazała się narzędziem trafnym i rzetelnym. Może być wykorzystywana w diagnozowaniu potrzeb rodziców w procesie choroby nowotworowej dziecka. Narzędzie to może być szczególnie przydatne na Oddziałach Onkologicznych, gdzie ważna jest troska nie tylko o małego pacjenta, ale również o jego rodziców.
Słowa kluczowe: choroba nowotworowa dziecka, kwestionariusz, ocena psychometryczna, sytuacja rodziców.

Introduction

In Poland oncological diseases are the second cause of death not only for adults but also for children. The recent data show that in 2019 the number of people aged 0-19 years (538 girls and 579 boys) who got cancer amounted to 1117 and the number of the children who died of it was 187 (74 girls and 113 boys) (Didkowska, Wojciechowska, Olasek, Caetano Dos Santos, Michałek, 2021).

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[1] Artykuł w języku polskim: https://www.stowarzyszeniefidesetratio.pl/fer/2023-1Soch.pdf

An oncological disease in a child is a traumatic event for the whole family, especially for the parents. The diagnosis of cancer itself or even the smallest suspicion of it can cause strong stress, which then accompanies the parents during the whole treatment process (Compas, Bemis, Gerhardt, Dunn, Rodriguez, Desjardins, Preacher, Manring, Vannatta, 2015; Malpert, Kimberg, Luxton, Mullins, Pui, Hudson, Krull, Brinkman, 2015).

When the child is ill, their family becomes a part of the medical care system. That involves new tasks for which the family is usually not prepared. They are connected with everyday visits or even an all-day stay in the hospital and care for the little patient as well as cooperation with the medical staff (Zavagli, Miglietta, Varani, Pannuti, Brighetti, Pannuti, 2016), approval of treatments or risky surgeries suggested by the doctors. It sometimes happens that such decisions must be made under pressure of time, which is a great mental strain for the parents. However, the studies show that the majority of parents accept doctors' decisions. Their attitude in such situations is more often passive than active (Salvador, Crespo, Roberto, Barros, 2020; Sisk, Kang, Mack, 2020).

Each stage of the struggle with their child's disease raises many fears. Most of the parents said that the most difficult thing for them was waiting for the diagnosis (83.9%), the diagnosis of a tumor (65.5%) and making a decision on treatment methods (68.3%). A significant and similar proportion of the respondents indicated some difficulties connected with the start of treatment (63.5%), hospitalization (61.4%) and the need to change the treatment (64.4%) (Wiener, Battles, Zadeh, Pelletier, Arruda-Colli, Muriel, 2017). It has been confirmed that even the recurrence of the disease is not as stressful for the parents as its initial diagnosis (Carlsson, Kukkola, Ljungman, Hovén, von Essen, 2019).

A long-term stress, uncertain prognosis, the need to be constantly available will make the parents of an ill child experience disadvantageous changes in their physical and psycho-social health (Agbayani, Tucker, Nelson, Martinez, Cortes, Khoury, Kain, Lin, Torno, Fortier, 2022; Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnell, Scott, Sung, 2008). The most frequent somatic complaints include: sleeping disorders, weakness, digestive system problems, loss of appetite, dizziness, and among mental complaints are: emotional problems, anxiety, depression (Agbayani et al., 2022; Northouse, Williams, Given, McCorkle, 2012; Zavagli, Varani, Samolsky-Dekel, Brighetti, Pannuti, 2012).

During the whole time of their child's disease, the parents feel physically and mentally exhausted. It turns out that suffering and problems with mental functioning keep appearing even 5 years after the treatment completion (Al-Gamal, Long, Shehadeh, 2019; Vrijmoet-Wiersma, van Klink, Kolk, Koopman, Ball, Maarten Egeler, 2008). 26% of the parents can develop the symptoms of PTSD. Its effects can last even up to 10 years after the diagnosis of an oncological disease in a child (Carlsson i in.,2019; Wakefield, McLoone, Butow, Lenthen, Cohn, 2011).

Struggling with the child's illness brings about problems in everyday life – in the family, professional and social spheres (Compas et al., 2015; Van Schoors, De Mol, Morren, Verhofstadt, Goubert, Van Parys, 2018). A long lasting disease of a child, which is always a great burden for the parents, has a negative effect on their marriage/partnership (Wiener, Battles, Zadeh, Pelletier, Arruda-Colli, Muriel, 2017). It makes it difficult to reconcile duties at home and in work with care over the ill child. It appears that such difficulties are reported by 70% of the parents (Peikert, Inhestern, Krauth, Escherich, Rutkowski, Kandels, Bergelt, 2020). They often have to reorganize their professional work or even give it up, which results in a decrease in the financial resources of the family and an increase in the expenses related to the treatment, care and rehabilitation. The biggest changes in employment have been observed in the parents of little dependent children suffering from hematological malignancies. That is a more frequent phenomenon when the family lives far from the hospital. Financial problems are not indifferent to the child's prognosis of recovery. There are situations when little patients have to undergo expensive surgeries, which significantly exceed the financial resources of the parents, and fundraising is often connected with fear and uncertainty (Roser, Erdmann, Michel, Winther, Mader, 2019).

The life situation of the parents of a child with an oncological disease depends on the support received not only from close people, friends, colleagues but also the medical staff in the hospital. It is very important in the aspect of the relationships with the partner, constitutes a buffer protecting well-being and mental health, contributes to better coping with stress and crisis caused by the child's illness (Carlsson et al., 2019; Peikert et al., 2020).

The parents report that they receive the greatest support straight after the diagnosis, but it decreases with the duration of the illness. They usually experience less social and emotional support (Christen, Mader, Baenziger, Roser, Schindera, Tinner, Michel, 2019) whereas the support from medical staff (institutional support) remains on a similar and beneficial level (Baenziger, Hetherington, Wakefield, Carlson, McGill, Cohn, Michel, Sansom-Daly, 2020). The contact with specialists may evoke concern or even anxiety, but it also gives the parents a sense of security (John, Injodey, 2018). What is important is the quality of the parents' relationship with the medical staff. The studies (Baenziger et al., 2020) show that their availability, support, openness, helpfulness can be a source of positive experiences. It can greatly improve coping with difficult situations connected with the treatment of the oncologically ill child.

1. Aim of Study

The aim of the study was to develop the Polish adaptation of *Life situation of parents of children with cancer* by Enskär, Carlsson, von Essen, Kreuger and Hamrin (1997)[2].

The life situation scale assumes an assessment of widely understood support, in which the authors of the tool (Enskär, et al.,1997) itemized, in the first assessment, twelve factors, which were finally reduced to four: quality of medical care, well-being, social contacts and support, readiness. The fourth factor – readiness – was excluded due to the low internal consistency.

Although in psychology there are a lot of questionnaire methods designed for measuring support, this one has a particular meaning since it is directed exclusively to the parents/guardians of oncologically ill children.

2. Method

2.1. Respondents

The participants of the study were 112 parents of oncologically ill children. The parents were at the age from 25 to 59 years (M = 38,56 years; SD = 6,71). The age range of the hospitalized children was from 1 to 17 years (M = 9,10 years; SD = 5,15). Only one of the parents could stay in the hospital and they were included in the study. The study covered the parents whose children were in the initial stage of treatment, i.e. six months from the diagnosis of an oncological disease. It was deemed important that all the respondents should be in a similar stage of treatment of their child's disease.

The conducted analyses did not take into account the age and gender of the ill children, the type of the diagnosed malignancy and the methods of treatment as the studies prove that they do not affect the functioning of the parents in a significant way (Phipps, Long, Willard, Okado, Hudson, Huang, Zhang, Noll, 2015).

2.2. Procedure

The study lasted from March 2019 to June 2022 and it was carried out in the Clinic of Pediatrics, Hematology and Oncology in Gdańsk, the Clinic of Pediatric Oncology, Hematology and Transplantology of K. Marcinkowski Medical University in Poznań and the Clinic of Pediatrics, Oncology, Hematology and Diabetes treatment of 1st Department of Pediatrics of M. Konopnicka Central Teaching Hospital in Łódź. The participants of the study were informed about the scientific purpose of the study, its anonymity and voluntary character.

The procedure of the adaptation of *Life situation of parents of children with cancer* (Enskär et al.,1997) included translation of the tool from English to Polish by two psychologists, fluent in English. Next back translation was performed by an English philologist. Both versions, English and Polish, were compared in

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[2] Consent has been obtained from Karin Enskär and co-authors to the Polish adaptation of *Life situation of parents of children with cancer*

order to check their equivalence. The factor structure verification was performed and the psychometric properties of the final version of the tool were assessed. The respondents filled the Life Situation Scale translated into Polish, consisting of 39 items, which they assessed on a five-grade scale: from 1 – definitely not, to 5 – definitely yes.

The procedures conducted in this study were compliant with the existing ethical standards. The research project was given a positive opinion by the Commission of Bioethics of Scientific Studies of University of Łódź (Resolution no. 3/KBBN-UŁ/I/2019 of 11th February 2019).

3. Results

3.1. Validity of Life Situation Scale

The factor structure verification of the Life Situation Scale was based on the results obtained from the studies of the group of the Polish parents of oncologically ill children. The statistical analyses were performed with the use of the SPSS Statistics software (PS Imago Pro 7.0, IBM SPSS Statistics 27, licensed by University of Łódź).

Exploratory factor analysis with Oblimin rotation of the main components was conducted with the assumption that the factors may be correlated with each other. After the substantive analysis of the statistical data, a three-component model was obtained, which included 20 statements. In order to verify the suitability of the sample to carry out the factor analysis, the Kaiser–Meyer–Olkin (KMO) test was used. In the created model, this measure is 0.748. According to Kaiser's (1974) recommendation, this value allows us to accept the suitability of the sample for carrying out the exploratory factor analysis. The result of Bartlett's sphericity test appeared to be statistically significant: chi 2 = 1209,002; df = 378; p < 0,0001.

The factor loads for the individual items are presented in table 1. They appeared satisfying, i.e. exceeding the required weight criterion on the level of 0.5 (Thompson, 2008).

Table 1. Factor loads for individual items of Polish version of LSS

Life Situation Scale Items	Factor 1	Factor 2	Factor 3
1. I receive support from friends or/and relatives	0.682		
2. I receive support from parents of children in a similar situation	0.574		
3. I receive support from medical staff	0.529		
4. I have understanding in my workplace	0.622		
5. The economic level of my family decreased	0.546		
6. I am positive about the future	0.521		
7. I feel alone in responsibility for the ill child		0.521	
8. I sometimes must be alone		0.627	
9. It is difficult for me to face the reactions of other people to the news about my child's disease		0.690	
10. I often feel lonely		0.666	
11. I often feel sad		0.589	
12. I have enough information about my child's disease, the treatment and coping with the situation			0.554
In the hospital I feel that:			
13. – I can decide about the situation of my child			0.682
14. – the doctor applies proper treatment			0.768
15. – the medical staff knows what they are doing			0.821
16. – the staff understands me and the needs of my child			0.756
17. – the staff is available whenever we need them			0.734
18. – I can contact the doctor whenever I need that			0.850
19. The hospital has all the necessary equipment			0.612
20. If needed, I can contact a social worker and a psychologist			0.626

Source: own study

The Polish version of the Life Situation Scale includes 20 statements, within which 3 factors were distinguished. Factor 1 – social support includes 6 items concerning support received from family, friends, relatives, medical staff, parents whose children are also ill as well as understanding in the workplace, which can be related to the financial situation of the family. Social support can determine the parent's general attitude. Factor 2 – emotional support covers 5 items, which describe well-being of the respondent in the situation of lack of emotional support. The effect may include the feeling of isolation, lack of understanding, sadness and even a tendency to wall oneself off from other people. Factor 3 – institutional support includes 9 items, the answers to which allow us to assess trust in and availability of medical staff as well as their readiness to provide information on the child's disease, the treatment and the ways how to cope with it and the feeling that the hospital has sufficient staff and equipment, which gives hope for recovery.

The names of the factors in the Polish version slightly differ from those in the original version. It has been decided that their sounding reflects the types of the measured support more clearly.

Like in the original version, the answers to the items are assessed on a five-grade scale, where 1 means "definitely not" and 5 – "definitely yes".

The (Pearson's r) correlation between the individual factors was checked (table 2).

All the correlations appeared significant. They occurred between social support and emotional and institutional support. The correlations between these factors appeared to be weak, which means that despite some probable similarities, there are also certain differences between these categories. The results shown in table 2 confirm the assumption about the existence of correlations between the factors and the admissible independence, which results from the theoretical premises.

3.2. Reliability analysis

The reliability of the Life Situation Scale was estimated with the use of the internal consistency coefficient – Cronbach α. It appeared satisfactory for each of the three factors. Allowing some correlation between the three factors, we also checked the reliability for the general result, which was satisfactory, too. The obtained Cronbach alpha values are presented in table 3.

3.3. Criterion validity of Life Situation Scale for Parents of Children with Oncological Diseases

The criterion validity was checked using the analysis of Pearson's r correlations between the scores on the Life Situation Scale – LSS, and the general score on the Multidimensional Scale of Perceived Social Support – MSPSS by Buszman and Przybyła-Basista (2017). All the tested correlations appeared statistically significant and positive (table 4). The strongest correlations were between general support on MSPSS and general support (r = 0,88) and institutional support (r = 0,741) on LSS. On the other hand, the correlation between MSPSS and emotional support appeared moderate (r = 0,557) and the one with social support – weak (r = 0,384). The obtained results allow us to assess the criterion validity of the Life Situation Scale as satisfactory.

Discussion of results and summary

The fact of struggling of the parents with the oncological disease of their child brings about difficulties in their physical and psycho-social functioning (Agbayani et al., 2022; Klassen et al., 2008). It is the consequence of a long-lasting fear for their child's health and life, monitoring the well-being of the little patient, making difficult decisions concerning surgeries suggested by the doctors. The parents find it hard to cope with too many duties, the time burden resulting from permanent stay in the hospital, which negatively affects their family and professional life (Peikert et al., 2020; Van Schoors et al.,2018; Zavagli et al., 2016). On the other hand, the presence and closeness of the parent is indispensable for the well-being of the child. Therefore, in the process of treatment of the little patient, it is very important to take care of their parents. Their ability to cope

Table 2. Correlation between factors of Life Situation Scale

	1	2	3
1- Social support	-	0,126*	0,216*
2- Emotional support	0,126*	-	0,113*
3- Institutional support	0,216*	0,113*	-

*p<0,05
Source: own study

Table 3. Reliability of three factors and general result of Life Situation Scale

	Cronbach alpha	Number of items
Social support	0.724	6
Emotional support	0.718	5
Institutional support	0.868	9
General support	0.846	20

Source: own study

Table 4. Matrix of result correlations of Life Situation Scale (LSS) – with general result of perceived support (MSPSS).

Support LSS	Perceived support - general result (MSPSS)
Social	0.384*
Emotional	0.557***
Institutional	0.741***
General result	0.888***

***p < 0,001; *p<0,05
Source: own study.

with this difficult, stressful life situation depends on the support they receive from not only the close people but also the medical personnel (Carlsson et al., 2019; Peikert et al., 2020). Therefore, it is necessary to do research on the perception of their life situation, and in order to do it, an appropriate tool is needed. Such a tool was developed by the Swedish researchers (Enskär et al.,1997). Conducting research in Poland required its adaptation.

The adaptation procedure for *Life situation of parents of children with cancer* covered verification of the factor structure and assessment of the psychometric properties of the Polish version of the Scale. The respondents qualified to the study were the parents of children who were in the similar – initial stage, i.e. six months from the diagnosis of an oncological disease. Each of the treatment stages can evoke a different attitude and emotions in the parents. It turns out that the most stressful stage is the initial one (Carlsson et al., 2019; Wiener et al.,2017).

The Polish version of the Scale of the Parents' Life Situation includes 20 statements and measures 3 types of support: social, emotional and institutional, i.e. received directly from medical staff.

A separate measurement for not only the individual factors but also the general index was adopted. The Polish Life Situation Scale turned out to be a valid and reliable tool. It can be applied in scientific studies and for diagnosing the parents' situation connected with their child's disease. This tool can be especially useful in oncological departments, where it is important to take care of little patients and their parents. Proper assessment of the parents' life situation not only allows us to learn about their needs, suggest effective therapeutic activities but also facilitates building effective communication between the guardians and the medical staff.

The conducted research is not without limitations. The main problem was to recruit participants to the study. It was carried out in the pandemic period. In fear of contracting infection with the corona-virus (SARS-CoV-2), it was impossible to enter the hospital. The study of the assessment of the life situation of the parents of oncologically ill children required a direct contact with the parents and in order to make the examined group consistent, it was assumed that it would cover the period of six months from diagnosing the oncological disease. Due to these difficult conditions, the group appeared to be not large enough, to carry out confirmatory analysis, which could support exploratory factor analysis. Therefore, it is important to continue research to verify the new tool.

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