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THE LEVEL OF PERCEIVED STRESS OF PARENTS OF CHILDREN WITH CANCEROUS DISEASE — MECHANISMS OF DEALING WITH STRESS AND SOCIAL SUPPORT

Abstract: **Introduction:** Cancerous disorders are the second most common cause of death among children. Blood cancer is a stressful and traumatic situation for the child, as well as the parents. To overcome the stress of child's illness parents adopt different coping styles. In overcoming these difficulties, the invaluable role is played by social support they receive from medical staff, family or institution.

Aim: To assess the feeling of stress for parents of children diagnosed with blood cancer, to determine how they choose to deal with stress in a difficult situation.

Material and Methods: The study group consisted of 63 parents of children diagnosed with blood cancer. The study used the PSS-10 scale to assess the stress experienced by parents, 40 GP ISEL scale to assess social support, Inventory Ways to Measure Coping and the author's questionnaire.

Results: High perception of stress was observed among parents. It was found that the strategy based on active coping (taking action to improve the situation) got the highest scores among the strategies for coping with stress. The study showed that parents can most often count on material support.

Conclusions: The feeling of stress severity among parents is high, particularly among women and people with higher education. The actions of medical team should take into account the needs of parents in raising and maintaining the resources to adapt to the difficult situation of child's disease.

Key words: leukaemia, parents, coping with stress, social support, stress.

INTRODUCTION

Leukaemia is the most common cancer in children under 18 years old [1, 2], viewed as a severe life-threatening disease, awakening fear and anxiety [3], which stems from the common belief that cancer inevitably leads to death [4]. A diagnosis of cancer in children also causes the presence of parents' painful, unpleasant emotions and feelings throughout the child's illness. This may initiate an existential crisis with feeling of emptiness and loss of meaning in life [5–9]. The possibility of occurrence of parents' crisis with a sense of burnout, physical, emotional and mental exhaustion, marked by a negative attitude towards themselves, their work and present life is also the consequence of the child's illness [7, 10].

The mechanism actuated in a stressful situation is adaptation of a specific style of coping with stress by parents, which may take adaptive form — the manifestation of peace and optimism towards the child, and trust in the therapeutic team or non-adaptive form — expressing uncertainty, fear for the life of a child, depression, fear and sadness because of child's illness [11, 12].

For parents of children with cancer the most adaptive style of coping with stress is the style focused on the task at hand. However, the avoiding style can also be effective, but taken only for a short time [13].

Knowing and understanding how to deal with stress of parents of children with a cancer diagnosis is extremely important because of the improvement of their emotional, mental and physical functioning, as well as providing psychological care for the whole family — during and after the end of treatment [6], in which social support plays very important role. According to Şek [14] social support is a kind of social interaction undertaken by one or both parties in a problematic situation in which there is informational, emotional or instrumental exchange, which may be either single or double sided, and the direction of the donor–recipient may be constant or variable [15, 16]. The purpose of the support is to bring participants closer in order to solve the problem and overcome the difficult situation. The effectiveness of support increases if there is compatibility between the type of support provided and the expected [17]. Support in terms of functionality can have emotional dimension (manifestation of empathy and caring) [18], informational (to facilitate understanding of the disease and to take effective measures in dealing with the situation) — the support gives a sense of meaning and understanding and a sense of control and efficacy [19–21], instrumental (information about specific ways of conduct) [22]. Support may also have a spiritual dimension which, for those who believe, gives a sense of meaning and hope in the face of life-threatening illness [23–26] and material support in the form of financial and material help [20]. Among the types of support there is the perceived support resulting from functioning of support networks and experiences in social relations, and the received support — the type of assistance and help actually received in a particular situation from the people within the support network [20, 27] The sense of support at each stage of child's treatment favours the adoption of attitudes focused on dealing with the difficult situation, which is the illness of a child [11, 28], and it is their decision whether and to what extent use and benefit from professional sources of support such as therapeutic team [29, 30].

Despite ongoing research in this area, it is still not possible to exactly determine what strategies to manage stress parents of sick children choose — because research has mainly focused on mothers of children with cancer.

The aim of this study was to try to assess perceived stress for parents of children diagnosed with blood cancer and to determine which ways of dealing with stress they choose in a difficult situation.

MATERIAL AND METHODS

The study included 63 parents (residents of Malopolska and Podlasie region) — 68% (N = 43) of mothers and 32% (N = 20) of fathers of children in the ages of 15–20 years with blood cancer, in a minimum of six months of diagnosis and treatment of their child. The parents voluntarily participated in the research after becoming familiar with its purpose. Tests were anonymous.

The average age of parents surveyed is 48.2 years old (SD = 5.6) — the youngest person was 38 years old (N = 1), and the oldest 62 years old (N = 1). Completion of higher education was declared by 32.0% (N = 20) of respondents, the largest group consisted of respondents with secondary education — 44.0% (N = 28) and 19.0% (N = 12) of respondents had vocational training, incomplete primary and primary education was reported by 2.0% (N = 1) and 3.0% (N = 2) of parents.

The largest group — 32.0% (N = 20) were people living in cities with more than 100 thousand inhabitants, 24.0% of parents lived in villages (N = 15). The remaining respondents — 44.0% (N = 28) lived in towns and urban areas (10 thousand to 100 thousand inhabitants). The most popular model of the family was a family with two children — 43.0% (N = 27). The average family had 2.4 children (SD = 1.0) and the average age of children with leukaemia was 16.8 years old (SD = 1.3) — the youngest child was 13 years old and the oldest 19 years old.

The study was conducted using the PSS-10 (Perceived Stress Scale) to assess the stress experienced by the parents, Mini-COPE questionnaire Carver's in order to assess typical reactions and emotions in situations of experiencing strong stress, and the author's questionnaire containing questions about gender, age, education of parents, and siblings of ill children, the scale of ISEL 40 GP (Interpersonal Support Evaluation List 40 GP) to assess their perception of social support — adapted by translator Zarzycka [31]. Mini-COPE and PSS-10 — adaptation of tools for the Polish — Juczyński [32].

The results were subjected to descriptive and comparative statistical analysis using Microsoft Office Excel 2007 and Statistica 2. The result statistically significant was decided to be $p < 0.05$.

RESULTS

The results of PSS-10 showed that the average level of stress in the study group was 21.25 (SD = 5.47). The low intensity of stress occurred among 11.0% of respondents (N = 7), the average severity of stress was observed in 24.0% of respondents (N = 15), high intensity stress was declared by 65.0% (N = 41) of parents. Gender of respondents had a significant impact on the severity of perceived stress — low and average severity of stress was felt by men. Women tend to feel high intensity of stress ($p = 0.0171$). Among other demographic variables — ed-

ucation turned out to be significantly associated with the experience of stress for the respondents: people with secondary and higher education experienced more severe stress, those with vocational education more often than other respondents felt stress at the average level ($p = 0.0060$).

The average score of ISEL 40 in the study group was 25.83% (SD = 6.78). The minimum value was 6 points and the maximum was 36 points. For individual subscales the highest score was achieved for financial support (M = 7.03, SD = 1.88). Slightly lower results were obtained on the scales of support from the membership (M = 6.40, SD = 2.04), and evaluative support (M = 6.35, SD = 2.01). The best results were found for the scale of self-evaluative support (M = 6.05, SD = 2.32).

Education of respondents significantly affected the assessment of social support and the assessment of support from the membership. People with higher education assessed social support higher than other respondents ($p = 0.0214$). Also, in the case of support from the membership, the respondents who have a university degree obtained higher values ($p = 0.0038$).

A significantly small statistical relationship concerned the place of living and the evaluation of social support — support from the membership was assessed lower by those living in rural areas. Higher ratings of support from the membership were indicated by those living in smaller and larger cities ($p = 0.0352$).

Statistical analysis has shown that the age of the child significantly influenced the assessment of social support — the correlation is negative, which indicates that parents of younger children assessed higher total social support ($p = 0.0104$), as well as support from the membership ($p = 0.0490$), self-evaluative support ($p = 0.0293$) and material support ($p = 0.0099$). In addition, a negative correlation between the number of children in the family and the assessment of financial support was found ($p = 0.0220$) — smaller number of children in a family affected higher scores of material support (Table 1).

The strategy based on active coping (M = 2.02, SD = 0.59) got the highest scores among the strategies of dealing with stress. High scores were associated to strategies based on the search for emotional support (M = 1.94, SD = 0.66), instrumental support (M = 1.89, SD = 0.71), planning (M = 1.86, SD = 0.62) and acceptance (M = 1.83, SD = 0.54). Lower results were obtained by such strategies to cope with stress as: turn towards religion (M = 1.75, SD = 0.80), discharge (M = 1.61, SD = 0.54), involvement in something else (M = 1.58, SD = 0.68), positive re-evaluation (M = 1.56, SD = 0.52). Strategies based on blaming yourself (M = 1.30, SD = 0.65) using psychoactive substances (M = 1.08, SD = 0.58), denial (M = 1.05, SD = 0.68), and sense of humour (M = 0.74, SD = 0.61) had the lowest scores.

The gender of respondents significantly influenced the strategies of coping with stress — women were more likely than men to turn toward religion in stressful situations ($p = 0.0243$), and seek emotional support ($p = 0.0098$) and instrumental support ($p = 0.0002$) (Table 2).

Table 1

Results of Evaluation of Social Support and child's age and number of children in the family.

| | | Child's Age | Number of Children in Family |
|-------------------------|-----------------------------------|---------------|------------------------------|
| Social support | Pearson's correlation coefficient | -0.3205 | -0.1972 |
| | p | 0.0104 | 0.1213 |
| Evaluative support | Pearson's correlation coefficient | -0.2094 | -0.1570 |
| | p | 0.0996 | 0.2191 |
| Support from membership | Pearson's correlation coefficient | -0.2491 | -0.0776 |
| | p | 0.0490 | 0.5455 |
| Self-evaluative support | Pearson's correlation coefficient | -0.2748 | -0.1389 |
| | p | 0.0293 | 0.2775 |
| Material support | Pearson's correlation coefficient | -0.3227 | -0.2882 |
| | p | 0.0099 | 0.0220 |

Table 2

Strategies for coping with stress and gender of respondents.

| Sex | N | M | SD | p | |
|------------------------------|----------|----|------|------|--------|
| Turn toward religion | Female ♀ | 43 | 1.91 | 0.79 | 0.0243 |
| | Male ♂ | 20 | 1.43 | 0.73 | |
| Seeking emotional support | Female ♀ | 43 | 2.08 | 0.66 | 0.0098 |
| | Male ♂ | 20 | 1.63 | 0.56 | |
| Seeking instrumental support | Female ♀ | 43 | 2.10 | 0.67 | 0.0002 |

Education of respondents had a significant impact on the choice of strategies of coping with stress. People with higher education more often chose planning under pressure, people with secondary education used it less often, and it was rarely chosen by people with vocational education ($p = 0.0356$).

The strategies based on active coping were least frequently chosen by the people living in towns up to 10 thousand residents ($p = 0.0123$). Strategies based on planning were most often chosen by people living in the cities of 50 thousand to 100 thousand residents, but they were hardly ever chosen by those living in towns up to 10 thousand residents and those living in cities with more than

100 thousand residents ($p = 0.0073$). Strategies based on seeking emotional support were the least frequently chosen by respondents who lived in towns up to 10 thousand residents ($p = 0.0325$).

Age of respondents, age of child with blood cancer and number of children in the family only to a small extent influenced the strategies to cope with stress chosen by the respondents. Strategies based on sense of humour were more often used by younger respondents ($p = 0.0195$). Use of psychoactive substances in stressful situations was more common among people who had older children ($p = 0.0485$). Denial and rejection of the existence of the stressful situation was often preferred by parents who had a larger number of children ($p = 0.0341$).

Analysis of the results has shown a limited relationship between the choice of strategies to cope with stress associated with the return to religion and the feeling of stress. People who felt higher intensity of stress more often turned toward religion in stressful situations ($p = 0.0352$). It was not established that the choice of other strategies of coping with stress was associated with Perceived Stress Scale.

People who chose strategies based on planning in stressful situations, higher assessed evaluative support ($p = 0.0098$), support from the membership ($p = 0.0205$), self-evaluative support ($p = 0.0249$), and material support ($p = 0.0230$).

Also, the overall result of social support was higher among those who in times of stress used this strategy ($p = 0.0038$). In addition, the survey has shown that the strategy of “positive re-evaluation” was more often chosen by people who valued support from membership higher ($p = 0.0311$). They also more often used the strategy based on sense of humour ($p = 0.0449$).

Analysis of the data have shown statistically significant negative relationships between the choice of strategy “Denial”, “Using Psychoactive Substances” and “Blaming Yourself” and the assessment of social support. People who often rejected the fact of stressful situation, assessed material support lower ($p = 0.0293$). Respondents who under stress often reached for stimulants assessed social support lower ($p = 0.0280$). Respondents who in times of stress often blamed themselves evaluated material support lower ($p = 0.0202$).

The studies have shown that there is a relationship between the experience of stress and sex of respondents. Intensity of stress was significantly higher among women than men. Feeling of severe stress involved 76.7% of women and 40.0% of men. The average level of stress was higher among males (40.0%) than among females (16.3%). Men also more often experienced low level of stress (20.0%) than women (7.0%).

The research has shown a statistically significant negative correlation between the assessment of social support and the age of the child — parents with younger children assessed social support higher than those whose children were older (Fig. 1).

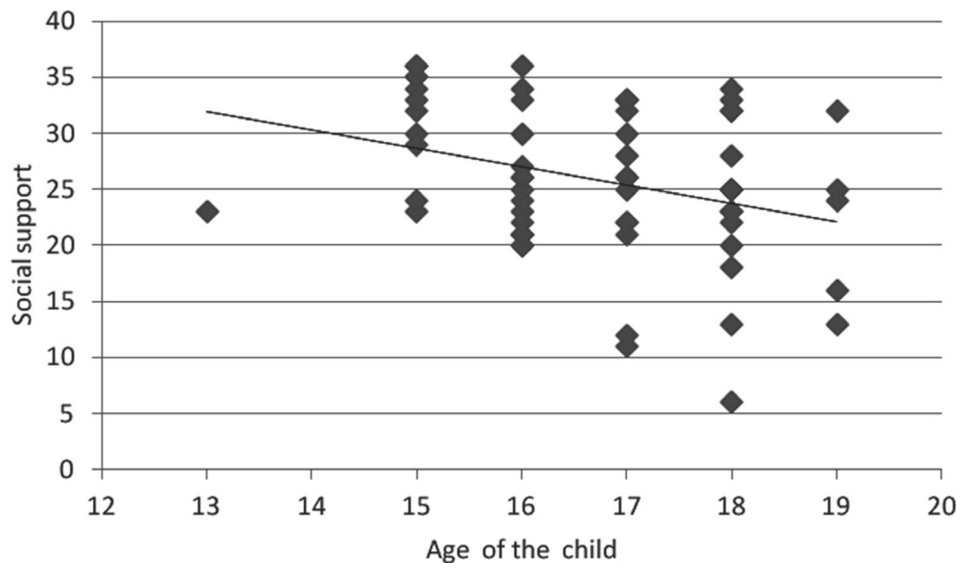


Fig. 1. Social support and the age of the child.

There is a statistically significant correlation between the assessment of support from the membership and the age of the child — parents of younger children evaluated support from the membership higher than parents of older children (Fig. 2).

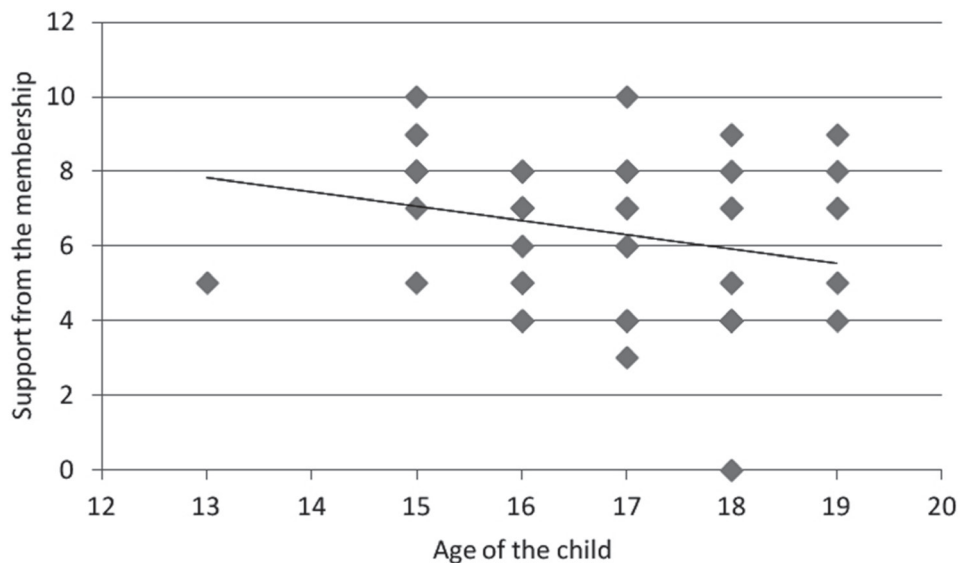


Fig. 2. The support from the membership and the age of the child.

In addition, the results have proven that the assessment of self-evaluative support is significantly related to child's age — parents of younger children assessed self-evaluative support higher than parents of older children.

Data analysis have also shown a significant negative correlation between the assessment of financial support and the age of the child — parents of younger children assessed material support higher than parents of older children. The studies have shown a statistically significant positive correlation between the choice of a strategy based on planning and evaluation of social support by the respondents. Those who evaluated social support lower were also less likely to choose planning strategy in case of stressful situation. People who chose this strategy evaluated social support higher (Fig. 3).

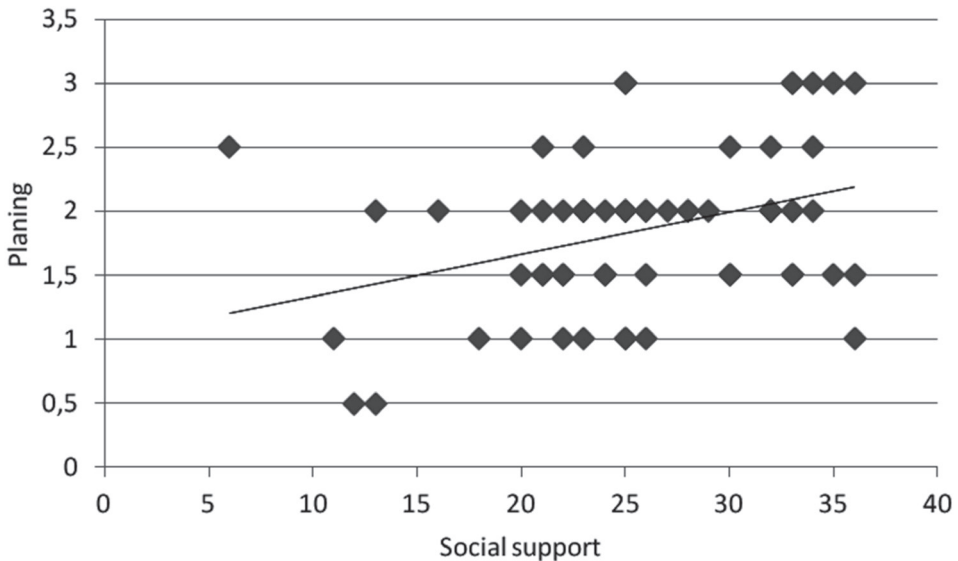


Fig. 3. Choice of a strategy based on planning and evaluation of social support.

DISCUSSION

Analysing the results of own studies, the assessment of stress level of parents whose children were diagnosed with blood cancer was prepared. Most respondents were characterized by a high perception of stress, especially among women and parents with higher education. As shown in the study, the fathers felt low and average severity of stress, the mothers more often experienced high stress intensity. Lepierz [33] in his study indicates that mothers more than fathers suffer from psychological disorders caused by stress which take the form of anxiety, depression, and insomnia. It cannot be ruled out that the low intensity of stress

in fathers is the result of more effective methods of controlling their emotions or ability to hide them. According Mastelarz-Migas et al. [30] high levels of stress may be associated with the fact that mothers are much more likely to accompany the child during the diagnosis and treatment of disease. Moreover, Pawełczak-Szastok *et al.* [34] pointed out that there is a need for a separate treatment of mothers and fathers of children with blood cancers because of their different needs and emotional functioning conditioned by gender. However, the results of some studies have not confirmed that, indicating adequate adaptation to a difficult situation, which is the illness of a child, and the average level of stress [35, 36].

In response to an apparent stress caused by child's illness parents use resources — called ways of coping with stress, which are understood as a permanent disposition of the entity for a particular struggle with stressful situations. The results of the study among parents of children with haematological malignancies indicate that the most commonly chosen strategies to cope with stress were: strategy based on active coping (taking action to improve the situation), strategies based on the search for emotional support, instrumental support, planning and approval (acceptance of the situation and learning how to live with it). Women are more likely than men to turn to religion and seek emotional and instrumental support in stressful situations, which is also confirmed in other studies [13, 19]. However, in the face of severe stress, turn to religion is not the most common way of coping used by both parents. It should also be noted that the choice of the strategy based on planning is significantly affected by the level of education of respondents (people with higher education use it more often). Psychology of positive thinking comes towards the problems related to stress situation. De Walden-Gałuszko [37] points to positive thinking as a way of coping with stress. On the basis of own studies, positive re-evaluation as a way of coping with stress, was chosen by most parents.

One of the best studied reservoirs of resistance to stress related to illness is social support — regarded as the type of interaction undertaken in the problematic situation or stress, which is aimed at solving the problem, overcoming difficulties and reducing the stress. Emotional and information support are the most commonly mentioned. Emotional support seems to be the most awaited by both children and parents. Emotional support provides a sense of security and stability [25, 14]. Research conducted by Cepuch *et al.* [19] has shown that emotional support is the least provided support in comparison to instrumental and information support. Our findings suggest that parents of children undergoing haematological treatment usually rated the availability of support from the membership, which consists of identification with the situation of other people. Parents also highly appreciate the material and self-evaluative support by comparing themselves with others. At the same time it is worth noting that people with higher education assess social support higher than those with low education.

The results obtained in the course of the study suggest that parents during haematological treatment of their children have a high intensity of stress; however, they are able to find the resources to deal with problems actively. Despite the difficult circumstances, they confirm the availability of material support, exhibit a higher level of acceptance of the child's illness.

Due to the small number of subjects, the results should be regarded as preliminary.

CONCLUSIONS

Feeling of stress for parents is high, particularly among women and those with higher education.

Providing support to parents at every stage of the struggle with the illness of a child seems to be a priority, providing the foundation to build a sense of security and enabling the process of acceptance of the child's illness.

The need for support is individually varied, but is important for parents.

The actions of medical team should take into account the needs of parents in raising and maintaining the resources to adapt to the difficult situation of child's disease.

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