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The perception of purpose and sense of life and satisfaction in young people with cancer and rheumatic disease

Abstract

Introduction. A cancer or rheumatic disease or and its associated bio-psycho-social connotations may affect the perception of purpose and sense of life in young patients. The intensity of emotional states and their changeability often obscures the boundary between physical and mental pain, significantly impinges on the lifestyle, threatens the basic values, the social roles played as well as the world outlook and their own identity. For someone entering adult life disrupted by a chronic illness and frequent attendant difficult experiences, the perception of purpose and sense of life acquires particular significance.

Material and methods. The study involved 124 young people of both sexes between 14 and 20 years of age hospitalised for cancer (group I — 82 patients) and juvenile idiopathic arthritis (group II — 42 patients). Pain intensity was measured the Visual Analogue Scale (VAS) and the Numeric Rating Scale (NRS), Cantril's Self-Anchoring Ladder was used to assess life satisfaction, whereas the PIL (Purpose in Life) Test was used to evaluate the perception of sense and purpose in life.

Results. Young patients registered high scores as regards their life, both current and anticipated and also demonstrated a clear purpose and sense in life regardless of group.

Conclusions. No significant connections between pain intensity and satisfaction in life were found. Such a result may have been influenced by the low pain intensity. Young patients demonstrated a sense of purpose in life, but their hierarchy of values and priorities in life was influenced by the kind of disease and the associated awareness of life in danger.

Key words: adolescents, satisfaction, sense of life, cancer, idiopathic arthritis, pain intensity

Introduction

Pain, prolonged course of disease, irregularity, stemming from the very nature of cancer or idiopathic arthritis as well as aggressive treatment may impact the perception of purpose and sense of life

determined by the level of hope of hopelessness experienced. According to Hinds et al. [1], having hope is an essential element of normal development of a young person suffering from an illness. The level of hope directly affects both the perception of self and the disease. However, hopelessness

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correlates negatively with the sense of self-esteem. The sense of self-esteem may influence the convictions as to the ability to achieve one's goals in the future and mitigate the influence of life's stress in older juveniles.

Adolescence constitutes an important stage in the shaping of self-esteem. Two elements play a key role in this respect: conviction as to an autonomous value of oneself as an individual and a comparison with others or evaluating oneself with respect to others [2–4]. Strengthening the sense of low self-esteem in children may be one of the factors predisposing to psychosomatic disorders. Bee [5] points out that during adolescence the sense of one's own self-esteem tends to fall significantly, and in situations where this is compounded by stress, both factors may play a considerable role in the emergence of depressive states.

Being diagnosed with a chronic disease associated with pain constitutes an extra burden that may, quite often, lead not only to diminished self-esteem, independence, disorders in the perception of one's own body or disrupted interpersonal relationships [6–10], but may also undermine the sense of life of a young person.

Frankl [11] — the originator of existential analysis — believes that man has a natural and specific need to seek value and the will to discover the purpose of his/her own existence, even in the context of suffering.

The sense of life may and should be experienced and lived through individually. Hence the natural at this age inclination to reflect, seek the sense of life, death, fate etc. may constitute a good perspective for psychotherapy or pastoral counselling (depending on the adopted philosophy of life). The aspect of faith may be important especially for the Polish society, which has not become secularised. Both emotional and spiritual maturity may lead to acceptance of one's condition and give sense to one's suffering.

Pilecka [12] states that if an illness is interpreted in terms of a task or a challenge, it may be an opportunity to develop a rich and internally mature personality. Patients who treat their illness as a worthwhile challenge, initiate cognitive processes leading to the finding of the sense and meaning of suffering, which fosters activities geared towards regaining health.

Adolescence is a period of time that completes the process of individualisation started in the first year of life and determines one's own, broadly conceived identity: psychological, psychosexual, interactive, social as well as determining the system of

values and purposes in life [5, 13]. Consequently, each illness, especially a cancer or a chronic condition, with associated pain related to the very essence of the illness, repeated painful diagnostics may destroy the existing external and internal orders of a young person [6, 14–17]. Therefore, it appears justified to attempt an assessment of the perception of purpose and sense of life and satisfaction in young people affected with a chronic illness with concomitant pain experience.

Material and methods

Research was conducted in Polish specialist institutions treating cancers and rheumatic diseases in children. Research among young people with cancers (KBET/395/B/2003) and in young people with rheumatic diseases (DK/KB/543/2003) was approved by the Bioethics Commission of Jagiellonian University and by the Independent Bioethics Commission for Scientific Research, Gdańsk Medical Academy (NKEBN/246/2003). At the same time, the above-mentioned health care units expressed written consent to conduct research among young people under treatment.

The study involved a total of 124 young people of both sexes between 14 and 20 years of age hospitalised for cancer (group I — 82 patients) and juvenile idiopathic arthritis (group II — 42 patients).

Studied were patients at various stages of the illness that lasted not less than 3 months and not more than 36 months. Patients treated with different groups of medications (Fig. 1). Patients with coexisting serious system or organ disorders were

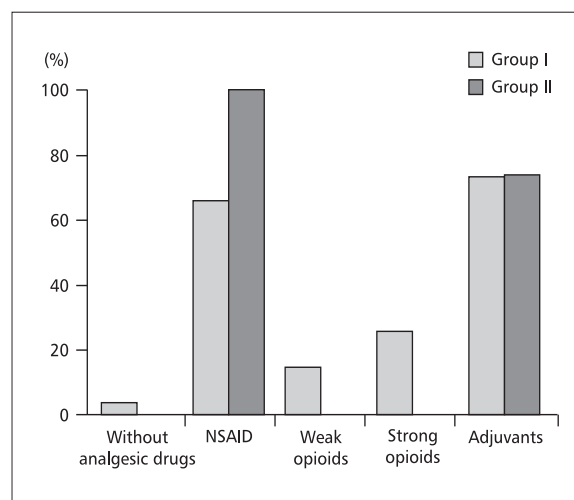


Figure 1. Groups of pain relieving medications given to patients; NSAID — Nonsteroidal anti-inflammatory drugs

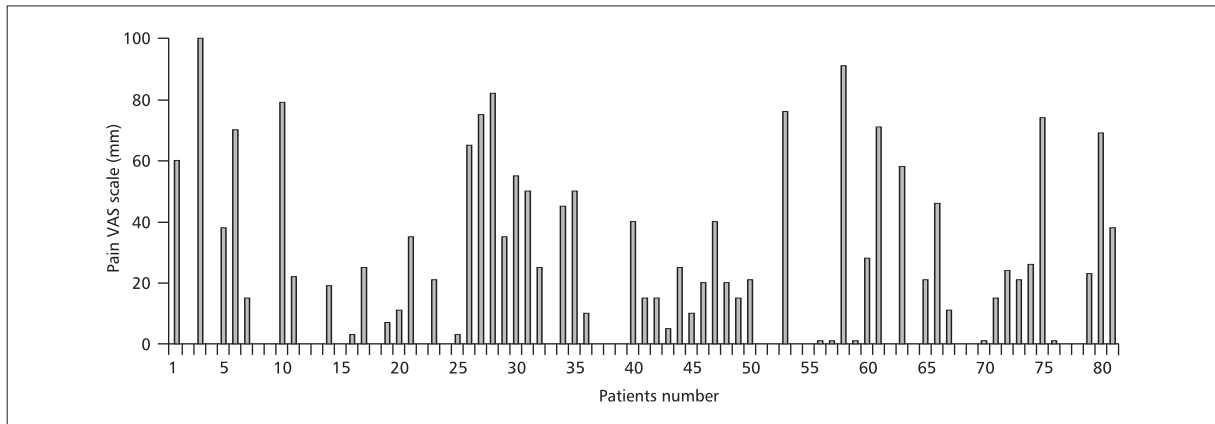


Figure 2. Pain intensity measured with VAS scale in particular patients (group I)

excluded from the study. For ethical reasons, terminal patients were excluded from the study. The qualifying pre-condition for the study was written informed consent both by the young patient and his/her legal guardians.

In order to assess pain intensity, we used the Visual Analogue Scale (VAS) and the Numeric Rating Scale (NRS).

Cantril's Self-Anchoring Ladder was used to assess life satisfaction. Appropriate modification of the instruction permits the evaluation of satisfaction with current, past or the future life. This method is usually represented graphically as a ladder. Its bottom is associated with "the worst life I could possibly expect" and scored as a zero, with the highest representing "the best life I could possibly expect" and scored as 10. The subject is asked to circle a place on the ladder where s/he thinks his/her life is at the moment (ladder 1) and where s/he thinks s/he will be after a certain time (ladder 2). The tool was standardised under Polish conditions. Low scores below 4 represent no satisfaction, whereas scores above 6 indicate higher satisfaction than in an average population [18].

The PIL (Purpose in Life) Test was used to evaluate the perception of sense and purpose in life [19]. The test was Adjusted for the Polish population in the Department of Clinical Psychology and Personality, Lublin Catholic University. In the study, parts B and C were used. Part B consists of 14 unfinished sentences to be completed by the subject with whatever first comes to their minds. The Polish version included questions about anxiety, satisfaction, sense of life and passions. In part C, subjects are encouraged to write several sentences about their aspirations, ambitions and aims in life. Owing to limited use of

some of the questions for the study (e.g. questions related to retirement), part A was left out, which had no impact on the final result since not all the questionnaire parts have to be used in the study. Patients' responses after processing were evaluated by a clinical psychology expert and the Chair of Mental Diseases of the Gdańsk Medical University.

The analysis of relationships between pain intensity and the evaluation of overall satisfaction in life using Cantril's Self-Anchoring Ladder was obtained by calculating Person's correlation coefficient, which was presented graphically as a distribution graph.

Statistically significant values are $p \leq 0.05$. Moreover, levels of significance were marked as follows: * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$.

Statistical analysis was conducted using the STATISTICA PLv.6 software package.

Results

Considerable percentage of patients participating in the study felt pain (Fig. 2, 3). A statistically significant difference ($p \leq 0.05$) was also observed among groups studied in terms of mean pain intensity measured using VAS. Mean pain intensity measured using the VAS scale, both for cancer and rheumatoid patient groups, was below 50 mm (Fig. 4).

Evaluation of pain intensity differed significantly between groups of patients, except the pain related to diagnostic activities (Fig. 5, 6).

Adolescents highly rated their satisfaction, both present and anticipated using Cantril's Self-Anchoring Ladder. No statistically significant differences were found among patient groups as regards present life satisfaction. However, when evaluating antici-

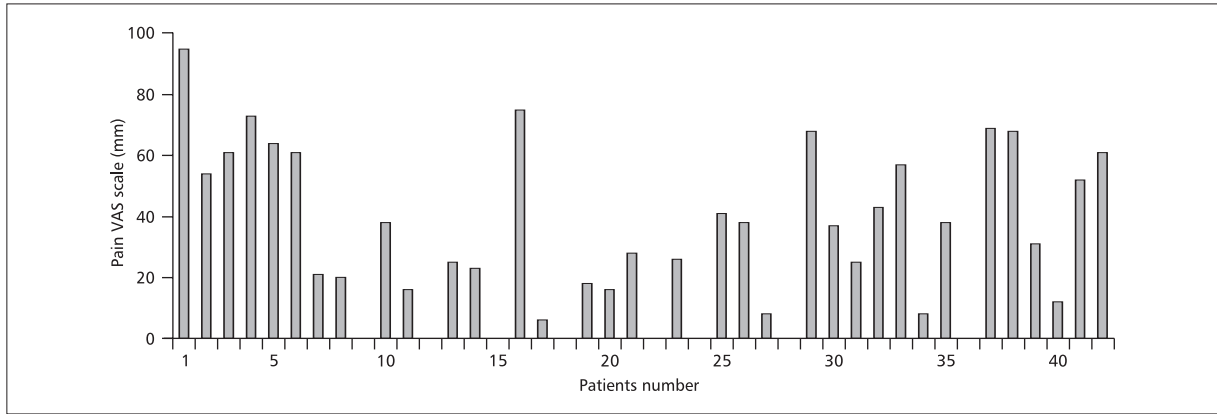


Figure 3. Pain intensity measured with VAS scale in particular patients (group II)

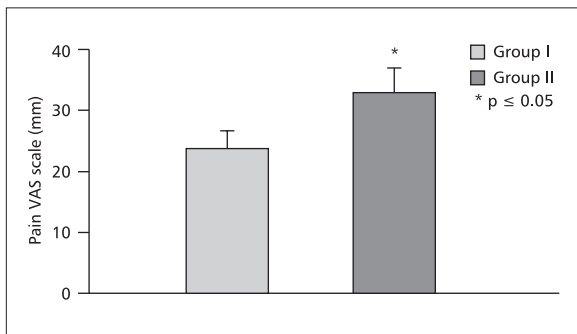


Figure 4. Pain intensity measured with VAS scale in both groups. (In order to improve legibility of figures the scale was limited to 40); Mean values were presented together with mean value error SEM

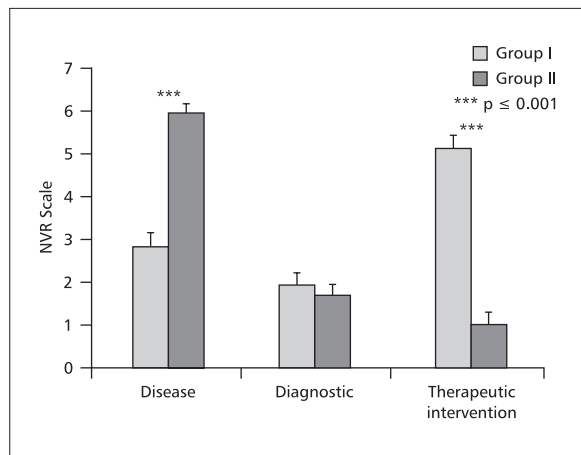


Figure 6. Pain intensity level vs. its cause

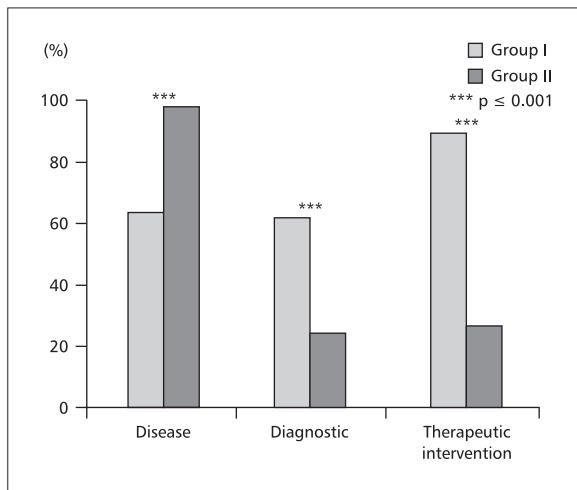


Figure 5. The cause of pain experiences

fraction anticipated in a year's time in both groups studied (Fig. 8).

Evaluation of perception of purpose and sense of life using the PIL Test — part B of the test:

Analysis of responses to parts B and C of the test started with mapping responses (sentence completions) to groups of categories constructed on the basis of similarity of psychological contents of these endings and frequency of their occurrence. No categories were imposed in advance, the categories have an empirical, not theoretical, grounding. The categories permitted the mapping of items (incomplete sentences) into higher-order categories, relatively consistent with respect to psychological contents. The following groups of categories were created:

- I. General evaluation of life and attitude towards present life (responses to sentences 12, 15, 17 and 24).
- II. Attitude towards the future (responses to sentences 2, 3, 5, 7).

rated satisfaction after a year, a statistically significant difference was observed ($p \leq 0.01$) (Fig. 7). No statistically significant were observed between pain intensity and life satisfaction „at present” and satis-

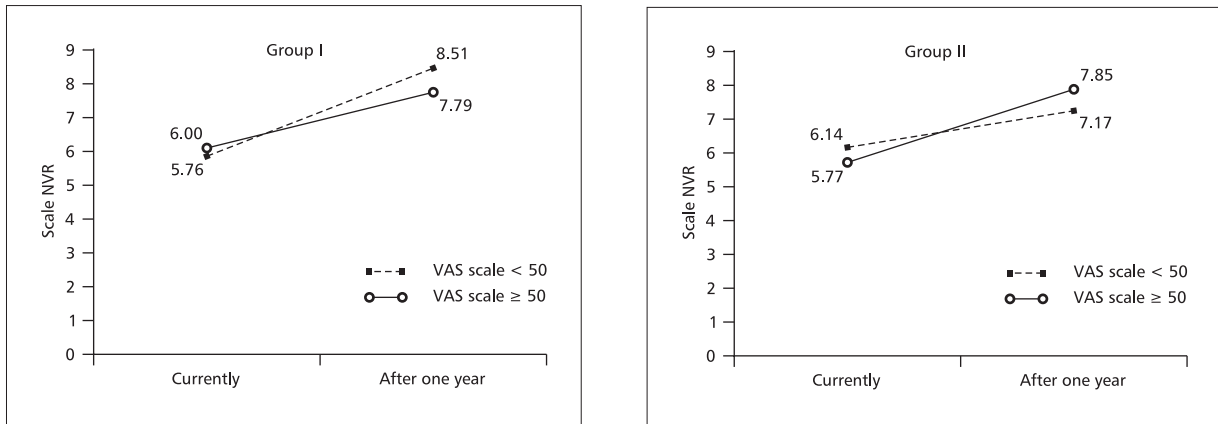


Figure 7. Assessment of satisfaction with life according to Cantril's ladder in both groups

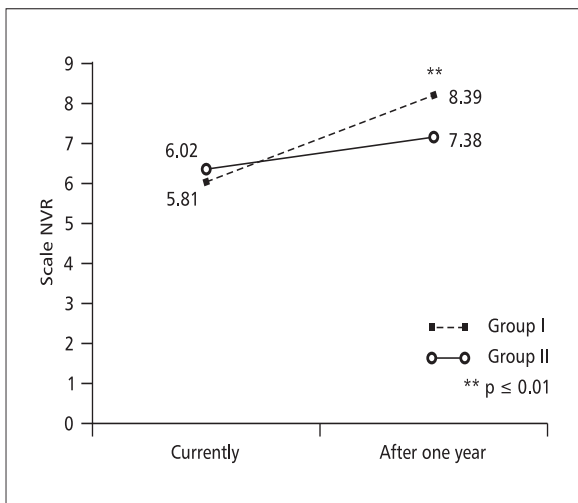


Figure 8. Relation between pain intensity and satisfaction with life according to Cantril's ladder in both groups

- III. Evaluation and attitude towards the past (responses to sentence 4).
- IV. Attitude towards suicide — suicidal thoughts (response to sentence 13).
- V. Attitude towards illness, death and suffering (responses to sentences 9 and 11).
- VI. Sources of hopelessness, helplessness, distress, anxiety (sentences 6, 8, 18, 23).
- VII. Obstacles and coping strategies (sentences 10, 14, 20).
- VIII. Positive aspects of life: hobbies, satisfaction, energy (sentences 16, 21, 22).

In part C of the test, on the basis of unscripted comments regarding ambitions and purposes, two categories have been created:

- 1. Positive evaluation.
- 2. Negative evaluation.

An analysis of the unscripted comments and the categories developed indicates the following:

1. No statistically significant differences among the groups of young people surveyed as regards the general evaluation of life and their attitude towards it (category I). A considerable number of adolescents from both groups demonstrated a positive attitude towards life (2/3 of those studied). For 87% patients, life was the highest value (Table 1, sentens 12). Health, love and friendship were among the most important values, followed by family. For 49.5% of respondents, the highest value was health (Table 1, sentens 17).
2. An evaluation of unscripted comments in the category Attitude towards the future (category II) showed a statistically significant difference was observed among groups of young people studied ($p < 0.001$). The differences were related to hope for achieving expected aims (Table 2). Cancer patients hoped for recovery. Rheumatic patients were more often concerned with happiness and love. Only in unscripted comments about the sense of life no statistically significant differences between groups were found. Most patients from both groups studied stressed that their aim in life is to achieve higher values, e.g. love and friendship (33.87%). The second most often quoted aim in life was to study and complete professional training. Aims related to health only came third. The most important ambition for patients in both groups was to graduate from school and have a profession.
3. There is a statistically significant difference among groups studied in category III — Attitude towards the past. Nearly 60% of all persons surveyed described their achievements in the past in very general terms, indicating a number of achievements. However, some patients, mainly from the cancer

Table 1. Results obtained in both groups from the sentence — Categories I, PIL B

Categories: sentence 12 — “For me, life is...”, and 17 — “In my life, it is important...”	Oncol. group	Rheum. group	p
Category I			
1. Emotional assessment — positive	47 (57.32%)	27 (64.29%)	NS
2. Cognitive assessment — positive	21 (25.61%)	13 (30.95%)	
3. Emotional assessment — negative	11(13.41%)	2 (4.76%)	
4. Rational assessment	3 (3.66%)	0	
1. Family	15 (18.29%)	9 (21.43%)	NS
2. Health	39 (47.56%)	15 (35.71%)	
3. Higher values	17 (20.73%)	11 (26.19%)	
4. Self-development	8 (9.76%)	6 (14.29%)	
5. No answer	3 (3.66%)	1 (2.38%)	

NS — no significant

Table 2. Results obtained in both groups from the sentence — Categories II, PIL B

Categories: sentence 2 — “I hope I can...”	Oncol. group	Rheum. group	p
Category II			
1. Hope for realisation of objectives in life	30 (36.59%)	10 (23.81%)	p < 0.001
2. Hope to overcome disease	27 (32.93%)	1 (2.38%)	
3. Self-development	19 (23.17%)	27 (64.29%)	
4. Hope for development of empathy	5 (6.10%)	4 (9.52%)	
5. Sense of helplessness	1 (1.22%)	0	

- patient group, did not perceive any success in their past (18.29%), whereas others indicated success in their fight against the disease (6.1%).
- No statistically significant differences among the groups of young people surveyed as regards their Attitude towards suicide (category IV). A vast majority of patients in both groups (82%) have a negative attitude to suicide and have never had such thoughts. But about 17% have had or are having suicidal thoughts, with somewhat more such thoughts being indicated by cancer patients (20.73%) as compared with the group of rheumatic disease patients (11.9%) (Table 3).
 - No statistically significant differences were observed in terms of their Attitude towards illness, death and suffering (category V). For ca. 42% of persons surveyed, death was decidedly negative, ca. 40% of young people are rational towards death, indicating its inevitability. The remaining patients (17.74%) described death in positive

- terms as: salutary, way to reach God etc. Nearly 63% patients from both groups associate illness and suffering with negative emotions, however 37 % of young people approached suffering and illness in positive terms.
- In category VI: Sources of hopelessness, helplessness, distress, anxiety statistically significant differences were observed as regards the cause of helplessness. Cancer patients felt helpless about their condition and its consequences, whereas rheumatic disease patients believed that helplessness was their individual feature and did not link it with their condition. At the same time, contrary to investigators’ intuitive judgement, nearly 22% of cancer patients had no sense of helplessness (Table 4). There were no significant differences among groups as regards the sources of their anxiety. For nearly 80% of young people surveyed, the source of anxiety was their health condition and uncertainty about

Table 3. Results obtained in both groups from the sentence — Categories IV, PIL B

Categories: sentence 13 — “Suicide is...”	Oncol. group	Rheum. group	p
Category IV			
1. Lack of suicidal thoughts	65 (79.27%)	37 (88.10%)	NS
2. Presence of suicidal thoughts	17 (20.73%)	5 (11.9%)	

NS — no significant

Table 4. Results obtained in both groups from the sentence — Categories VI, PIL B

Categories: sentence 18 — “I feel helpless because of...”	Oncol. group	Rheum. group	p
Category VI			
1. Diseases and results	22 (26.83%)	6 (14.29%)	p < 0.001
2. My own incapacity, weakness and helplessness	42 (51.22%)	35 (83.33%)	
3. Lack of sense of helplessness	18 (21.95%)	1 (2.38%)	

Table 5. The results gathered in both groups from the sentence — Categories VII, PIL B

Categories from sentence 20 — “I am kept from achieving my desires by...”	Oncol. group	Rheum. group	p
Category VII			
1. Diseases and results	52 (63.41%)	14 (33.33%)	p < 0.001
2. Age and personal slighly	12 (14.63%)	10 (23.81%)	
3. Socio-economic factors	3 (3.66%)	11 (26.19%)	
4. Nothing stops me	15 (18.29%)	7 (16.67%)	

Table 6. Results obtained in both groups from the sentence — Categories VIII, PIL B

Categories: sentence 21 — “I feel satisfaction...”	Oncol. group	Rheum. group	p
Cat VIII			
1. Satisfaction with quality of life experienced to that moment	37 (45.12%)	24 (57.14%)	NS
2. Satisfaction with having family and friends	15 (18.29%)	9 (21.43%)	
3. Satisfaction with struggle with the disease and adversities	20 (24.39%)	4 (9.25%)	
4. Lack of satisfaction and answer	10 (12.20%)	5 (11.90%)	

NS — no significant

- their future, whereas for 50% the illness and its consequences — suffering and pain — believed to be the source of their sense of hopelessness.
- There is a statistically significant difference between groups in terms of how they perceive the obstacles to achieving their aims and desires. Over 63% cancer patients saw the illness itself and its consequences as the major obstacle, whereas in the rheumatic disease group, only 33.33% of patients demonstrated such an attitude. Rheumatic disease patients indicated social and economic factors as their main obstacle to achieving their aims and desires, No differences between groups were found in problem-solving (Table 5). As many as 95% of respondents expressed decidedly negative opinions about solving problems by escapism and seeking oblivion in alcohol and drugs. Young people believed that the support and help of others is needed to overcome difficulties.
 - In category VIII: Positive aspects of life — passion, satisfaction, energy, significant differences were found in what they devote their energy to. Rheumatic disease patients more often devoted

their energy to self-development, whereas cancer patients much more often devoted their strength to fighting the disease (Table 6). No differences were found in comments about passions and satisfaction. Around 50% of patients had a sense of satisfaction with their lives. The sources of satisfaction were having a family, friends, overcoming the disease and adversities. Evaluation of the purpose and sense of life using part C of the PIL Test:

No connection between group membership and attitude towards life, its sense and purpose were observed. Among all the persons surveyed, 93.55% evaluated their life and their future in a positive way. Only a very small number of patients indicated the absence of the sense of life, ambitions and aims. No statistically significant relationships among the variables in question were observed. Results are shown in Table 7.

Discussion

The tendency for improved prospective satisfaction with life observed in the present study applied

Table 7. Results obtained in both groups from the the PIL Test, part "C": "Write some sentences about your ambitions and aims"

Categories	Oncol. group	Rheum. group	p
PIL C			
1. Emotional-cognitive assessment positive (e.g. health, life, self-development)	76 (92.68%)	40 (95.24%)	NS
2. Emotional assessment – negative (lack of achievements, no objectives and no sense of life)	6 (7.32%)	2 (4.76%)	

NS — no significant

both to the rheumatic disease and cancer patient groups, even though it was significantly higher in the latter group. It is hard to compare the results with these of other authors given the absence of similarly profiled studies in literature involving teenage cancer or rheumatic disease patients. It may only be suspected that the results obtained are related to patients' real or wishful hope related to full recovery. The present study involved an analysis of the relationships between patients' satisfaction with life and pain intensity, however, no significant relationships of the kind have been observed. It must be shown that pain intensity in both groups was not high, moreover, the study did not involve patients in a critical condition, which may have impacted the results obtained.

An evaluation of the sense of purpose and sense of life felt by patients using the PIL test indicates that regardless of which diagnostic group the patients belonged to, they evaluated their life in positive terms, both in regard of its cognitive and emotional aspects. For over one-half of all surveyed patients, the issue of illness and suffering is an important issue and inspires them to seek ways to understanding these phenomena in the context of such a psychological variable as the sense of purpose and sense of life. Young people consider health to be the most important value. This preference is undoubtedly related to the tangible sense of danger. However, in the present study it is hard to tell whether this hierarchy of values is a more idealised or real dimension. Despite that, it is very likely that for young people it constitutes an important area of their thoughts and feelings. As regards the attitude towards the future, groups surveyed were fundamentally different. Cancer patients much more often expressed their desire for health and preservation of life, and significantly more often expressed their hope of recovery. It appears that it results, among others, from the fact that the need to preserve health and life is more manifest owing to the threat to life brought about by the cancer than it is the case in rheumatic disease patients. Cancer still has very negative and fear-inspir-

ing social connotations. At the same time, patients from both groups wanted to achieve success in education and complete professional training.

Young people in both groups had a sense of success and achievement, which was evident, among others, in their attitude towards suicide. A significant percentage of patients have had no suicidal thoughts. Research publications by Maggiolini et al. [20], Karian et al. [21] and Novacovic et al. [7] prove that the experience of cancer for young patients may have a positive outcome, therefore it does not have to increase the risk of suicide attempts or the incidence of depression-related disorders. Results obtained in this part of the study confirm the results of similar studies conducted by the above-mentioned authors.

Patients' attitude to suicidal thoughts correlate with findings in their attitudes towards death. Most individuals surveyed demonstrated a decidedly negative attitude towards death, although some persons surveyed saw positive aspects of death, mainly in a religious context. A reference to the religious aspect of death may turn out to be very useful or even indispensable in young people with a terminal illness. Berde and Collins [22], Mc Coubrie and Davies [23] mention the possibility or even the necessity to implement a range of procedures geared towards spiritual support for patients and their families.

From the vantage point of coping with life's difficulties, what is important is a sense of strength and a firm conviction of the ability to cope with them. A sense of hopelessness is related to giving up the fight, hence it is important to detect the source or reasons for such a sense of helplessness, which has been demonstrated in this study. A vast majority of patients who viewed their situation as hopeless, saw the sources of their condition both in the illness itself, its negative consequences and in their own weakness. Rheumatic disease patients appear to be more empathic and indicate the suffering of their family and friends as the source of their own discomfort.

An evaluation of the presence of increased anxiety has shown that, irrespective of group membership, over 70% of surveyed patients are in a state of mental discomfort whose sources are predominantly their health condition and their future. This may be related to the awareness of the public regarding cancers, as well as the progress of the disease felt by the patients. Rheumatic disease has entirely different semantic connotations for the public. Maybe this is why rheumatic disease patients perceive the source of their sense of helplessness not in the illness itself, but in social and economic factors, as was shown by the results of authors' own research.

In the psychological description of patients' condition, what is important is not only the occurrence and description of negative emotional states, but also the presence of positive emotional states. Such positive states may constitute important mode of assistance in programming psychotherapy. The evaluation of satisfaction with life using Cantril's ladder and the PIL test has demonstrated that most patients (about 90%) from both groups felt satisfied with their life to date and its different aspects. Therefore young people whose life is in real danger, focus their thoughts and pursuits on fighting the disease, with successful results being the top priority. On the other hand, young people with rheumatic disease in whom there is no such threat, focus on self-development in order to match their healthy peers in terms of physical fitness.

The evaluation of ambitions, aspirations and aims obtained from unscripted responses of young people unequivocally points towards a strong sense of purpose and sense of their lives, regardless of the diagnostic group. Frankl's logotherapy indicates a route to inner harmony in the discovery of sense and specification of tasks to be performed. Young people who participated in the study have perceived sense of life and appreciated the values, which may be interpreted as their driving force and a will to live. The striving towards sense and values are one of the basic phenomena of being human [11, 24, 25].

Our research justifies the statement that in the vast majority of patients their illness did not result in the loss of their sense of life. For cancer patients, their fight for life, health and future became their purpose in life. Young people showed satisfaction with their lives, which has allowed them to maintain their optimistic attitude towards the future. However, it must be stressed that research did not involve clinically terminal patients or other patients who felt intense pain, which may have impacted our results. Research results unequivocally confirmed that

the group of young patients, especially those suffering from cancer, is one that exhibits special characteristics and needs that require individual attention and mode of procedure. At the same time, the results obtained confirm the fact that the biological, mental and spiritual dimensions are inseparable in man and must be taken into account when evaluating the patient's condition.

Conclusions

1. A vast majority of patients felt satisfaction with life, both currently and in the anticipated future. No significant analogies were observed between pain intensity and satisfaction with life. This may have been due to the fact that the experienced pain intensity was relatively low.

2. Young patients had a sense of purpose and sense of life. However, the hierarchy of values and priorities in life was influenced by the type of illness and the concomitant sense of life in danger.

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