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ORIGINAL ARTICLE

Profile of handicap situations in cancer patients

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Summary

Purpose: *The aim of this study was to assess the level of difficulty when performing a life habit, the type of assistance required and the person's level of satisfaction in relation to the accomplishment of each life habit, to establish a profile of handicap situation in cancer patients and to assess the relationship between the level of accomplishment and the level of satisfaction.*

Patients and methods: *The study sample consisted of 100 cancer patients. The Life Habits Assessment was used to measure the degree of accomplishment in 12 categories of life habits – daily living and social roles.*

Results: *Disruptions in the accomplishment of all life habit categories were revealed. The highest disruptions were observed in the following categories: education, recreation, and employment. The highest accomplishments were observed in communication, personal care, and fitness. Human assistance was required in the accomplishment of responsibility, community, employment and recreation. The highest person's level of satisfaction was observed in communication, personal care and interpersonal relations. The highest correlation between the level of accomplishment and the level of satisfaction were in mobility and residence, and the lowest correlation was in communication.*

Conclusion: *The established profile of handicap situation in cancer patients should help specify rehabilitation objectives and may be a frame for individual treatment plan in accomplishing better social participation of cancer patients.*

Key words: cancer, handicap situation, life habits, rehabilitation

Introduction

Nowadays, about 11 million individuals are diagnosed yearly with cancer worldwide. As we move into the 21st century, approximately 60% of newly diagnosed cancer patients are expected to survive more than 5 years [1,2].

Cancer has a major impact on the psychological, family, social and vocational aspects of the patient's life [3,4]. It may be potentially threatening for the individual's accustomed role and level of functioning. Potential threats include: threats to life and physical well-being, body integrity and comfort, independence, privacy, autonomy, and control of the newly established situation, threats to self-concept and fulfillment of customary roles, to life goals and future plans, to relationships with family, friends, and colleagues, to the ability to remain in familiar surroundings, and threats to economic well-being [5,6].

Despite consequences concerning their medical condition, cancer patients with impairment or a disability are not necessarily in handicap situations, provided the social organization is adapted and special support needs are met. Handicap situations are defined as "disruptions in the accomplishment of a person's life habits, resulting from impairments or disabilities, and from environmental factors" [7-10].

A life habit is defined as a daily activity or a social role valued by the person or his/her socio-cultural context according to his/her characteristics (age, sex and

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socio-cultural identity). Life habits ensure a person's survival, development and well-being in the society throughout life. This definition emphasizes the interaction between the individual characteristics linked to organic and functional consequences of diseases, and the environmental factors specific to a person's life [11,12]. Life habit accomplishment is measured on a scale ranging from full social participation to totally handicap situation.

Handicap situation is the interplay between the functional, behavioral or esthetic characteristics of the person and social factors such as access to programs and services, social roles, values and attitudes and ecological factors and technological development. This statement focuses on the role of the community as a whole in creating the handicap situation [8,11,13].

The higher rate of survival requires new interventions in cancer patients' comprehensive rehabilitation. The important part of the rehabilitation process is to assess the potential implications of cancer to activities of daily living. Despite the prevalence of cancer and functional impairments in patients, rehabilitation is not a common component of cancer treatment in most countries. One of the reasons of not performing rehabilitation in cancer patients treatment is the relatively few research reports documenting the patients' needs for rehabilitation, and any improvement after rehabilitation [14,15].

The purpose of this study was to contribute in the research concerning the assessment of social participation of cancer patients and their needs for rehabilitation. We aimed to assess the level of difficulty when performing a life habit, the type of assistance required and the person's level of satisfaction in relation to the accomplishment of each life habit, to establish a profile of handicap situation in cancer patients and to assess the relationship between the level of accomplishment and the level of satisfaction.

Patients and methods

Patients

This investigation was carried out at the Institute for Oncology and Radiology of Serbia, Belgrade, during the year 2005. One hundred of cancer patients were enrolled.

Eligibility criteria included confirmed diagnosis of cancer, lack of any another somatic or mental chronic disease and the patient's signed informed consent about participation in the study. The patient characteristics are shown in Table 1.

Table 1. Patient characteristics (n=100)

Characteristic	*Patients n*	*%*
Gender		
Male	40	40
Female	60	60
Age (years)		
Median	50	
Range	19-78	
Educational level		
Low	25	25
Middle	55	55
High	20	20
Type of disease		
Solid tumors	50	50
Hematologic malignancies	50	50

Methods

We used the standardized questionnaire "Assessment of life habits - LIFE-H (v 3.0)" to measure the degree of accomplishment in 12 categories of life habits - daily living and social roles [7]. The LIFE-H is a global tool determining disruptions in the accomplishment of life habits in persons with chronic disease and disabilities. The level of accomplishment is based on the degree of difficulty and the type of assistance required to achieve the life habit. An accomplishment scale (Table 2) was developed by the combination of two concepts: degree of difficulty and required assistance. A raw score was obtained for each life habit category by adding the accomplishment score of each applicable item. When a life habit was not carried out because it did not make up part of the person's daily life, it was considered non-applicable and was not factored into the raw accomplishment

Table 2. Description of the scale of accomplishment related to performance of life habits

Score	*Level of difficulty*	*Type of assistance*
9	Performed with no difficulty	No assistance
8	Performed with no difficulty	Technical aid (or adaptation)
7	Performed with difficulty	No assistance
6	Performed with difficulty	Technical aid (or adaptation)
5	Performed with no difficulty	Human assistance
4	Performed with no difficulty	Technical aid (or adaptation) and human assistance
3	Performed with difficulty	Human assistance
2	Performed with difficulty	Technical aid (or adaptation) and human assistance
1	Performed by substitute	
0	Not performed	
N/A	Not applicable	

score. The total LIFE-H score was obtained by adding the raw score of the 12 categories. The raw score of each category and the total score were expressed on a continuous scale from 0 to 10 in order to take into account variations in the number of applicable items for each patient. The formula for the accomplishment level (Weighted Score) and score transformation is given below:

$$\Sigma \text{ scores} \times 10 : \text{Number of Applicable Life Habits} \times 9$$

Statistics

Statistical analysis was carried out using the Spearman's rank correlation test and intraclass coefficient correlation (ICC) for relationship between the level of accomplishment and the person's level of satisfaction.

Results

Forty percent of the patients could not have meals in the restaurants, which was the important reason for disruption in accomplishment of nutrition (mean 7.24).

The important reason for occurrence of handicap situation in fitness (mean 8.74) was that 50% of the patients had sleeping difficulties, requiring need for taking drugs by 21% of them.

In performing personal care (mean 9.02) 28% of the patients had difficulty to use services provided by a medical clinic, hospital or rehabilitation center, and 26% of them needed human assistance in accomplishing this life habit.

For performing written communication (writing a letter, message; mean 9.12) 54% of the patients needed technical aid. Using a computer was impossible for 38% of the patients, which was the main reason for low level of patient's satisfaction.

In frame category life habit-residence (mean 7.07) 49% of the patients did not perform major household tasks (spring cleaning, painting, major repairs), 25% needed human assistance for maintaining home (cleaning, laundry, minor repair), and 14% needed technical aid or adaptation and human assistance for housing accomplishment.

Forty-nine percent of the patients did not perform riding a bicycle, and because of that they expressed the lowest level of satisfaction in performing mobility (mean 7.69). For driving a vehicle 9% of the patients needed human assistance.

Twenty-five percent needed human assistance for planning their budget and meeting their financial obligations (spending, saving, paying bills), 33% planned budget with difficulty, this being the reason for low level personal satisfaction in realizing responsibilities as a category of life habit (mean 8.34).

Forty-one percent of the patients did not perform sexual activities (healthy, appropriate, safe sex) in the frame of the accomplishment of interpersonal relations life habit category (mean 8.67). Five percent of them needed technical aid or adaptation in achieving sexual relations. Our patients expressed the highest level of dissatisfaction because of such reduced activities.

Community life (mean 8.29) was disturbed because 28% of the patients did not participate in social or community groups (social clubs, charity, or religious groups), resulting in low level of satisfaction. Human assistance in participating in spiritual or religious activities needed 12% of the patients. Participating in educational activities (mean 4.52) or vocational training at the high school level (courses, homework) was not applicable for 70% of the patients.

Forty-seven percent of the patients had difficulty in carrying out family or home-making tasks as their main occupation (mean 5.98). The lowest levels of satisfaction were expressed with seeking employment and holding a paid job. Twenty-two percent did not perform holding a paid job and taking part in unpaid activities (volunteering).

Forty-six percent of the patients did not go to sporting events, and 25% of them participated with difficulty in sporting or recreational activities (walking, sports, games; mean 5.28). Human assistance in accomplishing tourist activities (traveling, visiting natural or historic sites, camping) needed 9% of the patients, which was the main reason for their dissatisfaction (Table 3; Figure 1).

The results regarding the relationship between level of accomplishment and level of patient's satisfaction showed that in 7 categories of life habits - fitness, personal care, communication, mobility, responsibility, interpersonal relations, and community life - the level of accomplishment was higher than the level of patient's satisfaction. In 5 categories of life habits - nutrition, residence, education, employment and recreation - the level of patient's satisfaction was higher than level of accomplishment (Figure 2).

Regarding the relationship between level of accomplishment and level of patient's satisfaction, the highest correlation was in mobility and residence, while the lowest correlation was in communication (Table 4).

Table 3. Distribution of scores of accomplishment for the 12 category life habits

No.	*Category of life habits*	*Performed*		*Not performed*		*Not applicable*		*Total*	*Mean*
		No.	*%*	*No.*	*%*	*No.*	*%*	*%*	
1.	Nutrition	25	25	75	75	–	–	100	7.24
2.	Fitness	33	33	67	67	–	–	100	8.74
3.	Personal care	53	53	47	47	–	–	100	9.02
4.	Communication	32	32	68	68	–	–	100	9.12
5.	Residence	9	9	91	91	–	–	100	7.07
6.	Mobility	29	29	71	71	–	–	100	7.69
7.	Responsibility	31	31	69	69	–	–	100	8.34
8.	Interpersonal relations	30	30	70	70	–	–	100	8.67
9.	Community	48	48	52	52	–	–	100	8.29
10.	Education	13	13	23	23	64	64	100	4.52
11.	Employment	15	15	85	85	–	–	100	5.98
12.	Recreation	19	19	81	81	–	–	100	5.28

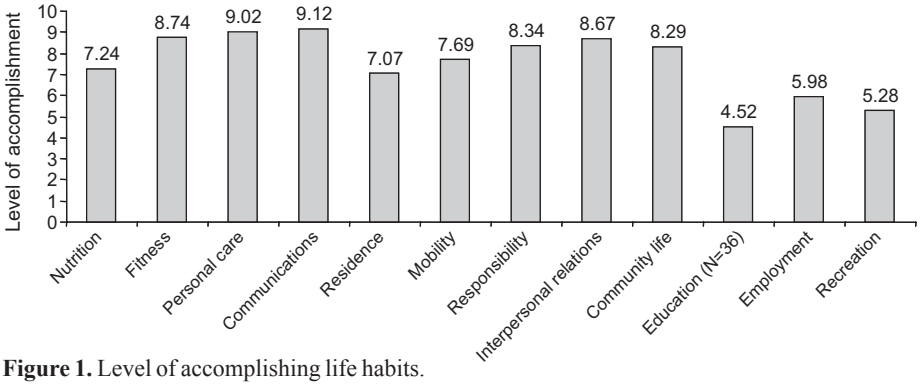

Figure 1. Level of accomplishing life habits.

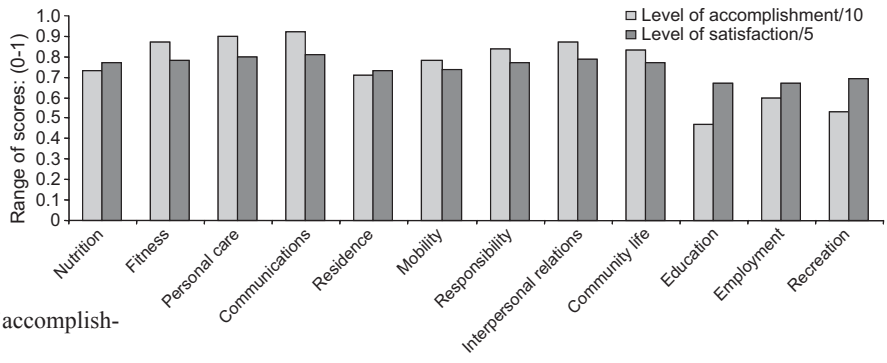

Figure 2. Relationship between level of accomplishment and level of satisfaction.

Table 4. Relations between level of accomplishment and level of satisfaction

	Category of life habits (range: 0-1)	*Level of accomplishment/10 (range: 0-1)*	*Level of satisfaction /5*	*ICC*
1.	Nutrition	0.73	0.77	0.51
2.	Fitness	0.87	0.78	0.52
3.	Personal care	0.90	0.80	0.41
4.	Communication	0.92	0.81	0.25
5.	Residence	0.71	0.73	0.63
6.	Mobility	0.78	0.74	0.64
7.	Responsibility	0.84	0.77	0.54
8.	Interpersonal relations	0.87	0.79	0.46
9.	Community	0.83	0.77	0.55
10.	Education	0.47	0.67	0.44
11.	Employment	0.60	0.67	0.53
12.	Recreation	0.53	0.69	0.41

ICC: intraclass coefficient correlation

Discussion

This study is a first step in the analysis of handicap situations in cancer patients in our country.

Difficulties in the accomplishment of all life habit categories were revealed. The highest disruptions were observed in the following categories: education, recreation, and employment, which are important for social integration.

The type of assistance required is a crucial element that has to be taken into account for evaluation, since a need for human assistance drastically changes the way that a person accomplishes a life habit when compared to an achievement that does not require any type of assistance.

Because of requirements of different types of assistance, especially human assistance, cancer patients had more disruptions in accomplishment: responsibility, community life, employment and recreation.

Our results showed that cancer patients were more in handicap situations when performing life habits with regard to social roles than performing daily activities. Disruption in performing social valued roles shows that cancer patients are not adapted in the new situation created by cancer, which could diminish self-esteem, reduce perception of control and may result in stigma [16,17].

Societal expectations define, by general standards, daily activities and roles that are acceptable. Individuals who deviate from expectations in any of these areas may be stigmatized. Stigmas often result in discrimination, social isolation, even threats to safety and well-being.

Our duty is to help cancer patients to establish a sense of their own intrinsic worth, despite their medical condition. During the adaptation process, patients need to diminish disability, compensate and substitute their physical impairment and limitations and to improve functional capabilities and skills.

A handicap situation indicates hopelessness when the possibility to make a choice is lost, when patients have no much option to overcome the situation, when family members or staff have to take care of them. Diminished self-esteem induces feelings of helplessness and useless, because of lost possibility to provide satisfying economic status both for themselves and their families [18].

Not performing sexual relationship may be a consequence of cancer itself, cancer treatment or its side effects, kinds of applied drug, age and general health condition. Lack of open communication between partners about sexual problems and needs is one of possible reasons for disruption of sexual relations [19].

The inclusion of measuring of satisfaction with life habits accomplishment is crucial in assessing the needs for additional support or intervention regarding personal choices or decisions for the patients' satisfaction, which is an indicator of quality of life [7].

The established profile of handicap situations in cancer patients should and could help specify rehabilitation objectives and may be a frame for individual treatment plan in accomplishing better social participation of cancer patients.

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