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Social participation of women with breast cancer

Uključivanje u društvo žena obolelih od karcinoma dojke

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Abstract

Background/Aim. The general problems of persons with malignant diseases (stages of asthenia, chronic fatigue and exhaustion, followed by depression and anxiety) lead to a decrease in functional abilities and a declining quality of life. The aim of this study was to determine the level of difficulty, the type of required assistance and the level of satisfaction that derives from maintaining life habits. The study also examined the correlation between the level of accomplishment of life habits and the level of satisfaction with how they are maintained. **Methods.** The research was conducted at the Military Medical Academy in Belgrade and in the "Get Together" Association of Women with Breast Cancer from June to September 2012 on a sample of 30 women. A standardised questionnaire, Assessment of Life Habits – LIFE-H v.3.0, was administered. **Results.** The lowest level of maintaining normal activities was related to education, housing and recreation. The greatest need for support to maintain normal activities was in the domains of housing, interpersonal relationships and employment. The greatest satisfaction in the accomplishment of normal activities was observed in the domains of mobility, nutrition and housing, and the lowest level of satisfaction was in the domains of recreation, communication and interpersonal relationships. The correlation between the level of accomplishment of normal activities and the level of satisfaction was the highest in the domains of general physical activity, responsibility and life in a community; the lowest level was in the domains of personal hygiene, housing, mobility, employment and recreation ($p < 0.001$). **Conclusion.** The results indicate that research participants found it more difficult to maintain their social activities than their everyday activities. This clearly indicates the necessity to develop and implement special advisory and educational programs aimed at preventing social exclusion and to strengthen and support personal resources in the area of the social roles of women with breast cancer.

Key words:
breast neoplasms; women; quality of life; questionnaires.

Apstrakt

Uvod/Cilj. Najčešći problemi osoba sa malignim bolestima (astenija, hronični umor i iscrpljenost, depresija, anksioznost) dovode do sniženja funkcionalnih sposobnosti i opadanja kvaliteta života. Cilj ovog istraživanja bio je utvrđivanje nivoa teškoća, vrste potrebne pomoći i stepena zadovoljstva realizacijom životnih navika, kao i usaglašenost nivoa realizacije životnih navika i stepena zadovoljstva sa realizacijom istih. **Metode.** Istraživanje je obavljeno u Vojnomedicinskoj akademiji u Beogradu i u Udruženju žena obolelih i lečenih od raka dojke „Budimo zajedno", u periodu jun–septembar 2012. godine, na uzorku od 30 osoba. Instrument procene bio je standardizovani upitnik za procenu životnih navika – *Assessment of life habits* – LIFE-H v.3.0. **Rezultati.** Najniže upražnavanje životnih navika prisutno je u obrazovanju, stanovanju i rekreaciji. Najveća pomoć u realizaciji životnih navika potrebna je u oblastima stanovanja, međuljudskih odnosa i zaposlenja. Najveće zadovoljstvo pokazano je realizacijom životnih navika u oblasti pokretljivosti, ishrane i stanovanja, a najmanje realizacijom životnih navika u oblasti rekreacije, komunikacije i međuljudskih odnosa. Najveća saglasnost između realizacije i nivoa zadovoljstva realizacijom životnih navika utvrđena je u oblasti opšte fizičke sposobnosti, komunikacija, odgovornosti i života u zajednici, a najniža u oblasti lične higijene, stanovanja, pokretljivosti, zaposlenja i rekreacije ($p < 0.001$). **Zaključak.** Rezultati ove studije ukazuju na to da ispitanice imaju veće teškoće u ostvarenju svojih društvenih uloga, nego u vršenju svakodnevnih aktivnosti. Ovo jasno ukazuje na potrebu izrade i primene posebnih savetodavnih i obrazovnih programa za sprečavanje socijalne isključenosti, ali i za jačanje i podršku ličnih mogućnosti u oblasti društvene uloge žena lečenih od karcinoma dojke.

Ključne reči:
dojka, neoplazme; žene; kvalitet života; upitnici.

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Introduction

The roles of medical care, special education, psychological support and social practice in the rehabilitation of persons with malignant diseases are of great importance. Every day, professionals all over the world strive to decrease the incidence of malignant diseases by methods of prevention and to increase the percentage of successful treatment of existing malignant diseases and improve cancer patients' quality of life [1]. The terms "quality of life" and "health-related quality of life" in particular refer to the physical, psychological and social domains of health, observed as distinct areas influenced by a person's experiences, beliefs, expectations and perceptions [2].

The general problems of persons with malignant diseases (stages of asthenia, chronic fatigue and exhaustion, followed by depression and anxiety) lead to a decrease in functional abilities and a declining quality of life [3]. Malignant diseases pose a threat to survival, physical integrity, autonomy, intimacy, self-control and self-esteem; delay or cancel life plans; disturb relationships with family, friends and co-workers; and endanger professional careers and financial situations [4].

Generally speaking, social expectations can affect daily life activities and social roles that should be adapted to surroundings. Life habits are related to the activities of daily living and the social roles that ensure survival and the lifespan development of an individual in society [5]. A person who deviates from such expectations has been 'labelled' as 'different' from the majority; possible consequences include discrimination, social isolation and the devaluation of one's abilities that affect the security and welfare of an ill person [6].

The consequences of malignant diseases and of specific oncologic treatments may have a great influence on one's functional abilities in all life domains. From the point of view of education and rehabilitation, a person with a malignant disease does not necessarily have to be prevented from accomplishing life habits; what the person can do depends on the interaction between the individual and environmental factors [7]. The main challenge to full social participation of persons with this disease is related to the lack of support programs and services, social measurements, values and societal attitudes, ecological factors and the technological progress of society [8].

The profile of life habits accomplishment in persons with malignant diseases as the correlation between the level of their accomplishment and level of their satisfaction with their accomplishments indicates the guidelines for the definition of specific goals and a plan for professional intervention to improve social participation and to change patients' personal perception of reality [9].

The prolonged life cycle of these patients reveals a new need for more complex rehabilitation of persons with malignant diseases. A valid assessment of the possible implications of cancer on everyday living and social participation is an important component of rehabilitation. Social participation is understood to be the complete accomplishment of life habits resulting from the interaction between the personal factors of an individual (the ensured integrity of the organ system and abilities) and different environmental factors (stimulating or non-stimulating).

The aim of this fundamentally descriptive study was to provide insight into the social participation of women with breast cancer as well as to assess the level of difficulty in accomplishing life habits, types of required assistance and level of satisfaction with the accomplishment of life habits, to assess the role of specific oncological treatments at the level of life habits accomplishment, and to analyse the correlation between the level of life habits accomplishment and the level of satisfaction with how the life habits were accomplished.

Methods

Thirty women with breast cancer disease participated in this study. The criteria for participants were as follows: age 20–65 years; minimum level of education – primary school; verified diagnosis of a malignant disease by histopathological results; localised stage of the disease; surgical intervention followed by radio- and chemotherapy; absence of physical, sensory or mental illnesses and conditions not connected to the malignant disease that would have a possible significant effect on life habits; patient's awareness of the diagnosis; agreement of the participants to participate in the study.

After a review of medical records, the patients who met the sampling criteria were chosen for the study. These patients were offered the opportunity to participate in the research, and the final sample comprised those patients who agreed to participate (Table 1).

Table 1

Patient (n = 30) characteristics

Parameters	Number of patients
Age (years)	
20–35	2
36–50	10
51–65	18
Type of oncology therapy	
chemotherapy	11
radiotherapy	2
chemo-and radiotherapy	17
Educational level	
low	2
middle	17
higher	9
high	2
Employment	
employed	4
unemployed	11
student	0
retired	15

The majority of the women were 51–60 years of age (n = 18) and had a high school education (n = 17). All of the participants were treated by surgical intervention, 17 of them had additional radio- and chemotherapy, 11 women had only chemotherapy and two of them were treated by radiotherapy only. Regarding their employment status, half of the partici-

pants (n = 15) were retired (Table 1). The research was conducted at the Military Medical Academy in Belgrade (n = 17) and the „Get Together" Association of Women with Breast Cancer (n = 13) from June to September 2012.

For the purpose of the research, the originally compiled questionnaire was utilised to obtain data regarding sex, age, education, employment status, type of therapy, etc. The Standardised Questionnaire for Assessment of Life Habits (Assessment of Life Habits – Life-H v.3.0) was also applied.

The LIFE-H assesses the accomplishment of life habits and the patients' satisfaction with how the life habits are accomplished (Table 2). The accomplishment scale of the LIFE-H covers all 12 domains of life habits proposed by the Disability Creation Process (DCP) model. The first six domains are related to activities of daily living (ADL): nutrition, fitness, personal care, communication, housing and mobility. The remaining domains are related to social roles: responsibilities, interpersonal relationships, life in a community, education, employment and recreation [10]. For each item on the accomplishment scale, the participants were asked about a perceived difficulty in performing a life habit (Table 3) and the type of assistance required to perform it. When a particular life habit was not part of the person's daily life, it was considered a non-applicable item [5, 8]. Satisfaction with each item was rated on a 5-point Likert scale ranging from 1 (very dissatisfied) to 5 (very satisfied).

The Assessment of Life Habits was developed to assess the quality of social participation of people with disabilities by estimating how a client accomplishes activities of daily living and fulfils social roles [8]. The questionnaire was standardised and validated in Serbian language and translated in two directions with the approval of the authors.

The participants were requested to answer two questions for each life habit. Question 1 determines, for each person`s life habit, the level of accomplishment (A) and the type of assistance required to accomplish it (B). Question 2 determines the level of satisfaction with the level of accomplishment for each of the person`s life habits (Tables 2 and 3).

The formula for the level of accomplishment (the weighted score) and the score transformation is presented below:

$$\sum \text{scores} \times 10 / \text{Number of Applicable Life Habits} \times 9$$

The mean values of 12 life habits accomplishment were weighted by the displayed formula.

Relevant parameters were described by the methods of descriptive statistics; correlations among variables were examined using ANOVA, Student-s *t*-test of arithmetic means for small samples and an Intraclass Coefficient Correlation (ICC) test.

Table 2

Questions and the format of the Questionnaire [10]

Live habits	Question 1		Question 2
	A Level of accomplishment	B Type of Assistance	Level of Satisfaction
Daily activities	No difficulty	No assistance	Very dissatisfied
communication	With difficulty	Assistive device	Dissatisfied
mobility	Accomplished by a	Adaptation	More or less satisfied
nutrition	proxy	Human assistance	Very satisfied
personal care	Not accomplished		
fitness	Not applicable		
housing			
Social roles			
responsibility			
interpersonal relationships			
community life			
education			
employment			
recreation			

Table 3

Description of the scale of accomplishment in the performance of life habits[11]

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

Results

The results of the investigation (Figure 1) indicate the level at which women with breast disease accomplished 12 life habits and their level of satisfaction with how the life habits were accomplished. The type of assistance required to maintain daily activities was presented in a descriptive manner.

For five of the participants, communication (mean score 8.47) did not include using a computer; for two of them, this way of communication was not possible; and in two cases, this life habit was accomplished with human assistance. Seven participants experienced difficulties in communication, and 10 of them required technical aids to read and understand written information.

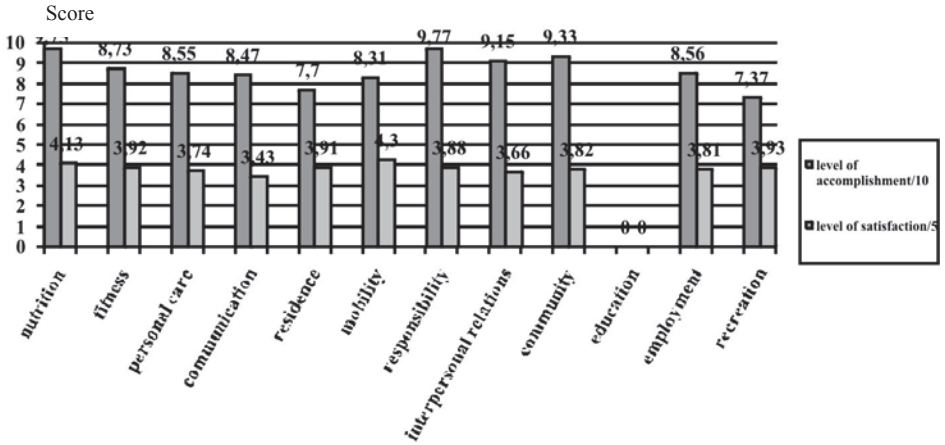

Fig. 1 – Level of accomplishing life habits and the level of satisfaction.

The ability to maintain nutrition (mean score 9.75) was significantly affected by the possibility of using restaurant services (three participants were not able to eat in restaurants and three did not); the greatest difficulties in this domain of life habits were related to preparing meals (three participants required some type of technical aid and human assistance). Although the level of accomplishment was high, the level of satisfaction with how the activity was accomplished (mean score 4.13) was lowest in the domain of selection of materials for food preparation and highest in the domain of using dishes and cutlery.

Regarding the ability to maintain fitness (mean score 8.73), one participant did not perform any physical activities, and two participants had no opportunity to perform this life habit to sustain and improve their health and physical condition. Eight participants did not practice relaxation exercises to improve their mental health whereas seven of them had no opportunity to practice yoga, meditation, chess, etc.

Regarding sleeping, 10 participants had some difficulty; however, only two spoke about technical aids in this domain. The women were generally satisfied with this life habit accomplishment (mean score 3.92); the lowest level of satisfaction was associated with the quality of sleep (comfort, sleep duration, depth of dreams, etc.).

Regarding personal care (mean score 8.55), 11 participants indicated that habits such as putting on, removing on and taking care of prosthetic aids were non applicable. Regardless of the difficulties in all of the aspects of this life experience, only three of the participants utilised technical aids in this domain. By assessing the level of satisfaction with how this life habit was accomplished (mean score 3.74), health care was at the highest level of satisfaction and using bathrooms and toilets out of home was at the lowest level.

The level of satisfaction with how this life habit was accomplished (mean score 3.43) was the highest in the domain of using a telephone (at home and at work) and lowest in the domain of using a computer.

In the domain of housing, housekeeping (mean score 7.70) was not available to 16 participants. Choosing an available house or a flat according to the specific needs of an ill person was a non-applicable habit for five participants and not possible for three participants. Difficult housekeeping tasks were a non-applicable habit for 11 participants, and for four of them, difficult housekeeping tasks were an unaccomplished habit; seven participants required human assistance with housekeeping activities. The level of satisfaction with how life habits in the domain of housing were accomplished (mean score 3.91) was reasonable; however, there were difficulties (the highest level of difficulty was in the domain of mobility at home, and the lowest level was in the domain of performing difficult housekeeping activities).

Mobility (mean score 8.31) by bicycle was an unaccomplished activity for 10 participants, and for 10 participants it was non-applicable. Driving a car was non-applicable for 20 participants, and for three it was an unaccomplished habit; only two participants were independent in performing this daily activity without difficulty or human assistance. The highest level of satisfaction (mean score 4.30) was in the domain of mobility on foot, and the lowest level was in the domain of driving a car.

In the domain of family and personal responsibility (mean score 9.77), three participants required human assistance, and the same number required technical aids. In five cases, using a bankcard was a non-applicable habit, and 10 participants did not support the education of their children. The level of satisfaction with how this life habit was accom-

plished (mean score 3.88) was the highest in using an automated teller machine (ATM) and the lowest in the domain of planning budgets and financial transactions.

Social support is a multi-factored concept that includes a number of interpersonal relationships and the quality of social relationships. Social support addresses care and empathy as well as obtaining goods, services and information. The support is provided by family, friends, health professionals, the religious community and other people in an identical life position [12].

Regarding interpersonal relationships (mean score 9.15), safe, healthy sex life was a non-applicable habit for eight participants; four participants had unaccomplished habits in this domain whereas five participants spoke regarding the need to accommodate sex life. Close relationships with children, parents, family members, friends and social connections were perceived as being conducted with difficulty in more than 10 cases. The life habits related to interpersonal relationships had a low mean score (3.66) on the subscale of satisfaction with how the relationships were accomplished. The highest level of dissatisfaction was with the participants' sex life (reducing or stopping sexual activities) and decreasing the level of close relationships with family members. The highest level of satisfaction was in the domain of close relationships with children. A malignant disease *per se*, the effects of therapy, negative effects from medications as well as aging, general health conditions, etc, could be factors in sexual dysfunction, which may also be explained by the lack of open communication between partners [13] regarding sexual problems.

Education in terms of professional training (high school level), college and university education, attending different training courses, craft and art education or professional and scientific work were activities that were non-applicable to all participants, indicating that education was the most neglected life habit.

In the domain of employment (mean score 8.56), four participants had no difficulties in choosing their jobs and professional careers, whereas for 13 participants, it was a non-accomplished habit; 30 women required assistance in looking for a job, and five participants were housewives who required help with housekeeping activities. The level of satisfaction (mean score 3.81) was the highest in the domain of "entrance and mobility at the workplace", and the lowest level was in the domain of looking for a job or choosing a job and career.

Quality of recreation activities (mean score 7.37) was mostly affected by attending sporting events; 23 participants did not accomplish this life habit whereas seven of the women participated in no outdoor activities (hiking, mountain climbing, camping, etc.) and did not use local recreation services. The highest level of dissatisfaction regarding how this habit was accomplished (mean score 3.93) was in the domain of travelling, using local tourist services and camping whereas the highest level of satisfaction was in the domain of manual jobs and handicrafts.

The type of oncologic therapy had a significant effect on life habits accomplishment in any of the assessment domains (Table 4).

Table 4

Correlation analysis between the type of oncology therapy and accomplishment of life habits

Parameters	The level of satisfaction with how life habits were accomplished and type of oncologic therapy		The level of accomplishing life habits and the type of oncologic therapy	
	F	Sig.	F	Sig.
Nutrition	1.479	0.246	0.379	0.688
Fitness	1.004	0.380	0.668	0.521
Personal care	0.515	0.604	1.354	0.275
Communication	1.013	0.377	0.384	0.685
Housing – Housekeeping	1.682	0.205	2.722	0.084
Mobility	0.248	0.782	2.680	0.087
Family and personal responsibility	1.985	0.157	0.073	0.930
Interpersonal relationships	0.632	0.539	0.364	0.699
Community life	0.170	0.845	0.901	0.418
Employment	0.445	0.649	1.460	0.250
Recreation	0.598	0.561	0.396	0.677

In the domain of community life (mean score 9.33), five of examined women did not participate in social, religious or spiritual groups or their events, and the participants did not require technical aids or human assistance for this life habit accomplishment. The level of satisfaction with how community life was accomplished (mean score 3.82) was the highest in the domain of "entrance into public institutions and just walking around" whereas the lowest level was related to participation in spiritual and religious events.

The correlation between the level of life habits accomplishment and the level of satisfaction with how life habits were accomplished was the highest in the domains of fitness, communication, responsibility and community life. The level of life habits accomplishment in the domains of nutrition and interpersonal relationships was not significantly correlated with the level of satisfaction (Table 5). Statistically significant correlations ($p < 0.001$) were observed between the level of dissatisfaction and life habits accomplishment in the domains of personal care, housing, mobility, employment and recreation.

Table 5

Relationship between the level of accomplishment and the level of satisfaction

Category of life habits	Level of accomplishment/10 (range 0–1)	Level of satisfaction/5 (range: 0–1)	Intraclass coefficient correlation
Nutrition	0.98	0.83	0.90
Fitness	0.87	0.78	0.93
Personal care	0.86	0.75	0.68
Communication	0.85	0.69	0.98
Housing	0.77	0.78	1
Mobility	0.83	0.86	0.89
Responsibility	0.98	0.78	0.87
Interpersonal relations	0.92	0.73	1
Community	0.93	0.76	0.50
Education	/	/	/
Employment	0.86	0.76	0.92
Recreation	0.74	0.78	0.99

Discussion

The aim of this study was to determine the level of difficulty, the type of required assistance and the correlation between life habits accomplishment and the level of satisfaction with how they are accomplished.

This study was conducted on a small sample (n = 30), thus, completely reliable conclusions cannot be derived. In addition, the sample included a wide age range of participants, a significant number of whom were retired; thus, the results related to life habits accomplishment in the domains of employment, education and child care may not be fully representative of all women with breast cancer.

Nevertheless, the study can help us understand the variations in life habits accomplishment and satisfaction with the activities' accomplishment in women with breast cancer at different ages. In addition, the study provides an overview of the accomplishment of 12 life habits and satisfaction with the accomplishment, which can be a strong basis for creating high-quality counselling programs and psychosocial education in the area of rehabilitation.

Life habits accomplishment in persons with malignant diseases has been studied by many researchers. A study of the quality of life and the psychosocial adjustment of women aged 65+ in the 15 months after being diagnosed with breast cancer [14] suggests a high level of satisfaction with physical and emotional functionality in the three months after the breast cancer surgery; however, contrary to other findings, this study showed a significant deterioration after that. Further, the deterioration was much greater in women who had breast cancer surgery (without additional radiotherapy) than in women who had radiotherapy only. This finding was explained by the number of comorbidity factors and chemotherapy treatment.

An investigation of the effect of psychosocial education in life adjustment of women after breast cancer treatment[15] observed that women who have had mastectomies show lower achievement in the domain of physical functionality than women in general population.

The first study in our country on the level of life habits accomplishment and quality of life in persons with malignant diseases [7] showed that there was no full social participation in any domain of life habits. Investigations on the level of life habits accomplishment in 100 participants with solid malignant tumours and hematologic malignancies showed that the participants were the most deprived of performing social roles in the domains of education, recreation and employment. Required assistance, especially human assistance in maintaining the activities of responsibility, community life, employment and recreation, had a great effect on decreasing the level of social integration. The results related to the correlation between life habits accomplishment and the level of satisfaction with how activities are accomplished may be summarised as follows: in seven of the categories of life habits (fitness, personal care, communications, mobility, responsibility, interpersonal relationships and community life), the level of accomplishment was higher than the level of satisfaction. In the other five domains (nutrition, housing, education, employment and recreation), the level of satisfaction was higher than the level of real life habits accomplishment. The highest correlations were in the domains of mobility and housing, and the lowest correlation was in the domain of communication.

Systematic education can be a strong supporting model for persons with malignant diseases. By actively learning about the disease, treatment and strategies of copying with malignancy, cancer patients acquire new tools in the struggle for a better quality of life (adapting to the new experience, overcoming the feelings of fear and insecurity connected to the disease and therapy). Educational programs should be created from the patient's perspective on the basis of evaluation of previous knowledge, actual needs, specific wishes, requirements and interests because full understanding as well as usefulness of information always depend on the capacity of individual people [16].

Conclusion

The expected benefits of the study were related to noting the importance of social participation (by life habits accomplishment) in women with breast cancer as well as emphasising the need for education and rehabilitation in oncology. The results indicate the social difficulties in life habits accomplishment in persons with malignant diseases, and also

directions for possible intervention in the course of this process facilitation.

The results of our study show a great number of unaccomplished life habits associated with social roles accomplishment (education, recreation and employment); life habits associated with everyday life activities (nutrition, personal care, communication, mobility, responsibility) were accomplished to a greater extent.

The highest levels of satisfaction with how life habits were accomplished were in the domains of mobility, nutrition and housing, and the lowest levels of satisfaction were in the domains of recreation, communication and interpersonal relationships. According to the obtained results, intraclass coeficient correlation analysis indicates the highest correlations between the level of life habits accomplishment and the level of satisfaction in the domains of fitness, communication, responsibility, interpersonal relationships and community life and the lowest level in the domains of personal care, housing, mobility, employment and recreation. It was not shown that the type of oncology therapy had a significant effect on life habits accomplishment in any domain of assessment.

The results obtained in this study clearly indicate the necessity of developing and implementing special advisory and educational programs aimed at not only preventing social exclusion but also strengthening and supporting personal resources in the area of social roles of women with breast cancer.

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