

NECESSITY OF SELF-MANAGEMENT SUPPORT FOLLOWING COLORECTAL CANCER TREATMENT

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ABSTRACT

Introduction. Many studies have shown that patients with colorectal cancer have to be educated to self - manage their condition and improve the quality of their physical, mental and social life after cancer. Self-management support is broader than health services alone, because it can include support from other cancer survivors, community, online, family, friends etc.

The aim of current study was to analyze the patient's satisfaction of medical treatment and health care and, on this basis, to determine the necessity of self-management support following colorectal cancer treatment.

Material and methods. The current study included 315 patients with colorectal cancer. The participants were residents of seven different Bulgarian regions. The applied methods were documentary and questionnaire (anonymous), listing questions referring to the patient's lifestyle and attitude to the disease.

Results and discussion. Of the investigated patients, 37.8% esteemed the quality of medical care as good, and only 16.2% affirmed it was excellent. The level of diagnosis and treatment competency was given a good and very good estimation by 64.5% of the respondents and 64.1% gave the same esteem for physicians' good attitude. Dissatisfaction was revealed

RÉSUMÉ

Nécessité d'un soutien à l'auto-gestion suite à un traitement du cancer colorectal

Introduction. De nombreuses études ont montré que les patients atteints de cancer colo-rectal doivent être formés à l'auto-gestion de leur état afin d'améliorer la qualité de leur vie physique, mentale et sociale après le cancer. Le soutien à la gestion autonome est plus vaste que les services de santé tout seuls, car il peut inclure le soutien d'autres survivants du cancer, de la communauté, de la famille, des amis, etc.

L'objectif de l'étude actuelle est d'analyser la satisfaction du patient sur le traitement médical et les soins de santé, et sur cette base pour déterminer la nécessité d'un soutien de l'autogestion après un traitement contre le cancer colo-rectal.

Matériel et méthodes. L'étude actuelle a porté sur 315 patients atteints de cancer colo-rectal. Les participants étaient des résidents de sept régions bulgares différentes. Les méthodes appliquées étaient documentaires et questionnaire (anonyme), énumérant des questions se référant au mode de vie et à l'attitude du patient à l'égard de la maladie.

referring to psychological counseling activities – a total of 54.6% of the respondents. A relatively small part of the investigated individuals (20%) required discretion concerning their disease state.

Conclusion. The current study established a significant relationship between patient's satisfaction and the necessity of self-management support to help for better life quality.

Keywords: colorectal cancer, self-management, self-management support.

Résultats et discussion. Parmi les patients étudiés, 37,8% estiment que la qualité des soins médicaux est bonne, et seulement 16,2% ont affirmé que c'était excellent. Le niveau des compétences de diagnostic et de traitement a été évalué par 64,5% des répondants et 64,1% ont donné la même estime à la bonne attitude des médecins. L'insatisfaction a été révélée en ce qui concerne les activités de conseil psychologique – soit 54,6% des répondants. Une partie relativement faible des personnes interrogées (20%) exigeait une discrétion quant à leur état pathologique. L'analyse statistique non paramétrique a révélé des relations significatives entre cette caractéristique spécifique et les questions pertinentes énumérées dans le questionnaire.

Conclusion. L'étude actuelle a établi une relation significative entre la satisfaction du patient et la nécessité de s'engager dans le soutien de l'auto-gestion pour aider à améliorer la qualité de vie.

Mots-clés: cancer colo-rectal, auto-gestion, soutien à l'autogestion.

INTRODUCTION

Although new evidence emerged during the last decade concerning the diminishing prevalence and mortality rate of colorectal cancer (CRC)^{1,2}, the global data presenting the leading position of CRC referring to diagnosis rate still prevail, shifting backwards a number of other cancer diseases. Colorectal cancer occupies the third place, following lung and prostate cancer, among men, and the second place among women, after breast cancer^{3,4}. This disease is still a serious health challenge associated with yet unresolved issues referring to its prevention and treatment. The role of self-management among the recent diversity of measures and approaches for effective CRC treatment is more and more often emphasized. Many studies have shown that patients with colorectal cancer have to be educated to self – manage their condition and improve the quality of their physical, mental and social life after cancer^{5,6,7}.

The term self-management signifies the patient's active engagement in the treatment process. Thomas Creer introduced this term for the first time in his book on rehabilitation of chronically ill children, published in 1960⁸. The author explained the necessity of behavioral interventions and patients' healthy lifestyle for the success of their treatment. He included this term in programmes for prevention and treatment of asthmatic state in children who, being an active participant in the curative process, contributed to its effectiveness⁸.

Very quickly, the „self-management“ approach was introduced in the therapy and care processes associated with various chronic diseases, including CRC. In relation to CRC patients, the self-management soon became an important issue because of the introduction of complex therapeutic regimes, often involving the administration of numerous combinations of chemotherapeutic medications and other types of health care interventions⁹. Different scientific studies have shown that self-management support is broader than self-management alone, because it can include support from different sources, as other cancer survivors, community, online, family, friends, etc¹⁰⁻¹².

The researchers studying this problem usually distinguish two groups of patients: patients living longer after the determined diagnosis and patients that live over a long time with the disease sequences¹³. The treatment of those patients must comply with the individual specifics and the disease progress stage¹⁴. The patient's mental state caused by the disease is hard to estimate. The precision of the estimate is important for the introduction of the two approaches – Self management and Self-management support. The provision of support plays an essential role in the realization of effective self-management. Effective methods of support for patients' self-management are the various training forms, consultations with patients regarding their motivated involvement in the therapeutic activities, dissemination of materials to promote their awareness. The National Cancer

Survivorship Initiative includes a shift towards support for self-management, including self-directed follow-up¹⁵.

Considering the scientific interest to the support of self-management of patients with colorectal cancer, we aimed to analyze the patient's satisfaction with medical treatment and health care and, on this basis, to determine the necessity of self-management support following colorectal cancer treatment.

MATERIAL AND METHODS. The current study included 315 patients with colorectal cancer, after surgical intervention, visiting consulting rooms from eight different Bulgarian regions. The applied methods were documentary and questionnaire (anonymous), listing questions referring to the patient's lifestyle and attitude towards the disease. This survey is part of a more comprehensive study on risk management, with a focus on health services provided to colorectal patients. The survey included only some questions from the questionnaire study associated with the disease-induced attitude and mental state of the respondents. Descriptive statistic was used for data processing.

RESULTS AND DISCUSSION

Table 1 presents the results of the answers to the question: „Are confidentiality and discreetness observed during the treatment period?“

Table 1. Confidentiality and discreetness.

N°	Esteem	Number	Valid Percentage rate
2	15	4,8	5,0
3	14	4,4	4,6
4	47	14,9	15,6
5	77	24,4	25,5
6	149	47,3	49,3
Total	302	95,9	100,0
No answer	13	4,1	
Total	315	100,0	

The results showed particular patients' satisfaction regarding the confidentiality and discreetness during the treatment course. The validated percentage rates of the opinions „very good“ and „excellent“ were 25.5 and 49.3%, respectively. These data revealed the psychological attitude and showed, on one hand, fear from the disease with fatal exit and, on the other hand, the hope for full recovery or getting into a remission period. In such conditions, the role of health management is crucial and it should be included mandatorily into the set of therapeutic

approaches and psychotherapeutic methods. The contact with the therapist and the therapeutic team, in the form of support with observed confidentiality to a great degree, preserve the patient's confidence in the positive treatment outcome.

One very important question associated with the patient's disposition is „whether the disease will affect the personal lifestyle and occupational abilities and activities“. The results of the answers are listed in Table 2 (2.1.), showing the prevalence of anxiety and embarrassment among the majority of respondents – 239, 156 of them with a categorical „yes“ and 86 answering „I do not think about that“. The feeling of uselessness, the need to be cared for by their spouses or parents, the incapacity to cope by themselves – all those lead to loss of dignity, besides the negative disease outcome. The last answer, indicative for serious doubt in the disease outcome, possibly related to the real health status, is confusing. Besides that, it could be supposed also that the patients are interested only in their health status, with everything else having no importance, staying in the background that has a more optimistic character. The health management should engage in this aspect, including self-management support, to raise the possibility for optimistic disease outcome. The number of respondents convinced that colorectal cancer will not affect their abilities and activities is relatively small. Improved health status could be expected for this group of patients, due to their optimism, which, supplemented with an adequate support by the therapeutic team, healthcare specialists and their environment, could lead to cancer survival.

The results of the answers to the question: „What are the chances for recovery and survival?“ are shown in Table 2 (2.2). The defeatist thinking is characteristic for most patients but it is most pronounced in cancer patients. The reasons are as follows: the disease is incurable in an advanced stage and, even in an early stage, there is no guarantee that after the remission the disease will not occur again. That is why the thought of fate and the constant stay in hospitals, resection of body parts lead to disturbed normal life rhythm and make the patients dependent on drugs, without clear image whether they could plan their life activities, even in short time periods. All that experience brings about inferior life quality when the patient searches for information that could mainly inspire more optimism. Thus, besides his own awareness, he needs the information and discussion with his supervising physician and with the individuals he is in contact with. The content of Table 2 shows the positive attitude of 123 individuals or 39% of the respondents, who replied that they were well informed and had the disposition towards convalescence. The

number of patients (105 patients, 33%) who, though well informed, could not evaluate their chances for survival, was relatively lower. The third group, represented by 55 individuals (17.5%) also demonstrated high awareness, though with low survival chances. The smallest group (21 persons, 6.7%) replied that they had no information. In general, having in mind the results on that question, it could be supposed that the respondents consider their awareness sufficient, but the evaluation of the survival is unclear and insufficient. The numbers referring to those considerations are listed in Table 2, unambiguously

determining the necessity of supportive environment, including self-management support.

The answers to the question „Is the word „cancer“ a taboo for you and your family?“ are presented in Table 2 (2.3.). They provoke the necessity of a comprehensive discussion, as they incorporate not only the patient’s level of awareness on the disease, but also his psychoanalytical and cultural component, completed with need for various support types specific for their environment.

In this regard, the social support plays a very important role in chronic diseases, related to acquiring

Table 2. Awareness, concern, attitude, estimate of recovery chances.

N°	Esteem	Number	Percentage rate	Valid percentage rate
<i>2.1. Concern about functions execution and patient's abilities</i>				
1	Yes	156	49,5	54,5
2	No	47	14,9	16,4
3	I do not think about that	83	26,3	29,0
Total		286	90,8	100,0
No answer		29	9,2	
Total		315	100,0	
<i>2.2. Awareness and recovery chances</i>				
1	Well, attitude towards recovery	123	39,0	40,5
2	Well, I cannot assess	105	33,3	34,5
3	Well, low chances	55	17,5	18,1
4	I am not well informed	21	6,7	6,9
Total		304	96,5	100,0
<i>2.3. Is the word „cancer“ a taboo for you and your family?</i>				
1	Yes	63	20,0	22,4
2	No	218	69,2	77,6
Total		281	89,2	100,0
No answer		34	10,8	
Total		315	100,0	
<i>2.4. Can you easily talk with your relatives about your disease</i>				
1	Yes	150	47,6	50,2
2	No	41	13,0	13,7
3	Sometimes	108	34,3	36,1
Total		299	94,9	100,0
No answer		16	5,1	
Total		315	100,0	
<i>2.5. How do you envisage the future?</i>				
1	Gloomy and hopeless	41	13,0	13,8
2	With small hope	148	47,0	49,8
3	Everything will be in order	108	34,3	36,4
Total		297	94,3	100,0
No answer		18	5,7	
Total		315	100,0	

information about the disease and suffering; to diminish the uncertainty – the chronic disease is accompanied by uncertainty referring to whom and how it will be realized the treatment, what the future will bring to the patient; to establish a feeling of certainty. The social support is effective if the chronically ill person evaluates it as adequate and is satisfied with it. In case of very serious diseases, the patients do not want those around to be informed about their status. This attitude is common for cancer patients. This discreetness means that they would not like to be regarded as doomed, because their hope for recovery is stronger than the feeling of despair. It should be noted that only 20% of the respondents acknowledge that the word „cancer“ is a taboo, while the other 69.2% openly announce their disease without striving for discretion. The number of the patients who have not entered an answer is relatively large – 34 or 10.8%. For them, we suggest that they could be assigned to the first group (setting a taboo on „cancer“). We could consider a good result the large number of patients that are not afraid to admit their disease. This result is probably due to the significant prevalence of colorectal cancer, as well as to the growing amount of information about the necessity of prevention of this disease.

The question „*Do you share with your relatives about the disease?*“ is of more particular character compared to the previous question influenced by the individuality of the certain person and his emotionality. Table 2 (2.4.) lists the answers to this question.

Most patients never learn to talk to their relatives about the disease, as the frequent reminding or discussions disturb their normal life rhythm and everything is oriented towards the cancer. In order to avoid this process, the patients rarely talk to their relatives, except if they are not with positive disposition and consider this only as a life stage that they have to overcome. Many of the investigated persons in our survey answered that they speak easily with their relatives, which means that a large percentage of the patients undergoes the treatment with the hope to achieve a positive health effect. Few people answered negatively, enabling the suggestion that they hide their feelings that could cause aggravation of the problems and lack of positive treatment effect. The answer „sometimes“ is interesting and we could hardly discuss, because of the lack of additional information to substantiate the use of the „sometimes“ word. Though, applying the scientific-speculative approach, we would differentiate the patient's relatives into parents, spouses and relatives. It is clear that the patient's sincerity will be quite different towards those groups, thus the „sometimes“ answer finds its particular place. Patients with CRC, especially after

surgical intervention, have a natural feeling of deep embarrassment. The next question flows logically: whether the patient's relatives support him after they have understood the diagnosis. The data (Table 2) categorically confirm the relatives' support (225/71.4% of the respondents). Only 13 of a total of 299 respondents answered negatively (4.1%). The „sometimes“ answer is given by 61 persons (19.4% of all respondents). The last answer could be regarded as inconvenience to clarify concretely some interrelations in the family or among the victim's relatives. The general conclusion is that the good understanding and empathy of the relatives, acquainted with the diagnosis, providing their support to the ill person, is an important condition to achieve an effective treating process. We do not know if this support is provided in an adequate form, because of unavailable data about the awareness level and cultural competency of the victim's relatives. It is, though, sure that additional activities are necessary, concerning not only the patient but also his environment – source of support.

Table 2 (2.5.) presents the answers to the question „*How do you envisage your future?*“ This is a very difficult question for every cancer victim. The analysis of the answers is clearly shown in the Table. The number of respondents – 41 – who accept their state as hopeless and see the dark future is the smallest. Those patients need the more active intervention of the health manager, aiming to achieve optimal psychic state and raising the optimism. In contrast to this group come the answers of 108 respondents, who state that they will overcome the disease and everything will be in order in the future. This psychological arrangement is an excellent basis for effective treatment of the colorectal carcinoma. The number of respondents with small hope for optimistic outcome is not small – 148 individuals. Generalizing the meaning of the answers, we could easily affirm that the respondents of this survey show a great degree of optimism in relation to the progress of the therapeutic process and are a very appropriate contingent for effective health management, including the mandatory components of self-management and sources of self-management support.

CONCLUSION

The necessity to raise the level of awareness about the prevention and treatment of colorectal cancer is undoubted, as well as the inclusion in the complex of various cares of self-management and self-management support. The current study established a significant relationship between patient's satisfaction and the necessity of engagement in self-management support, to help for better life quality. The selection

of support type should be individually-oriented and, if possible, with maximally extended framework, in order to achieve the desired comfort in the lifestyle of patients with colorectal cancer.

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