

# Selected psychosocial aspects of life of patients with a stoma

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Received: 22.03.2016. Accepted: 19.05.2016.

## ABSTRACT

Cancer causes huge problems, physical and mental nature mainly. In particular, we cannot forget about the functioning of these patients in the social and spiritual spheres. The increasing trend of incidence of rectal cancer makes the disease is becoming a priority for doctors, nurses and psycho-oncologists. Despite the increasing quality of medical services, patients face a number of problems associated with cancer treatment, which may result in formation of a colostomy. The procedure, which is necessary to save the patient's life, is often perceived by them as "mutilation". Acceptance of the disease and satisfaction of life in patients with a stoma after the operation for rectal cancer are dependent on many factors. Social support, living conditions and the time elapsed since creation of the stoma have great impact. "Stoma nurse" plays an extremely important role. Seeing the difficulties in adapting the stoma she should verify the patient's pessimism as to his/her own self, develops a sense of responsibility from minor to major issues and strengthen a sense of independence.

**KEY WORDS:** stoma, colorectal cancer, psycho-oncology

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In recent decades, a growing tendency of cancer incidence in the world can be observed. Each disease, cancer in particular, cause huge physical and mental problems mainly. We cannot forget about the functioning of this age group within the social or spiritual spheres. Colorectal cancer is a major problem of modern oncology.

According to the American Cancer Society (ACS), 142,570 people in Europe are affected with this cancer and as many as 51,370 people have died in 2010 [1]. It is estimated that about 70% of colorectal cancer is located in the colon and 30% in the rectum. Cancer of the rectum is described as cancer expanding 12–15 cm from the junction of the skin and mucosa (crested lane) to recto-sigmoid flexure [2]. Treatment of colorectal cancer is often connected with necessity to form a stoma called colostomy. It is a junction between colon lumen and skin surface made during surgery. It can be temporary or permanent in nature [3].

Epidemiological data on the incidence and mortality of colorectal cancer are alarming. The incidence of rectal cancer is estimated at 15–20 people/100,000 inhabitants/year in the Member States of the European Union. The mortality rate ranges from 4–10/100,000 inhabitants/year depending on the region [4]. Rectal cancers are more common in men than in women. Rectal cancer occurs mainly in people over 50 years of age [2]. Scientific studies provide information on the incidence and mortality depending on the race. It is estimated that the highest morbidity and mortality of this disease occurs among African Americans and lowest among Hispanics, Asians and those living in areas of Alaska. Caucasians belong to a group with an average incidence of colorectal cancer [2]. Geographic diversity also has a significant impact on the incidence and mortality rates. Incidence is highest in industrialized countries such as the US, Canada, Australia and Western and North European countries. Regions with the lowest incidence include Africa and Asia [2].

The increasing trend of incidence of rectal cancer makes that the disease is becoming a priority for doctors, nurses, psycho-oncologists. Despite the increasing quality of medical services, patients face a number of problems associated with the treatment, often linked to form a colostomy. Acceptance of the disease and satisfaction of life in patients with a stoma after the operation for rectal cancer are dependent on many factors. Social support, living conditions and the time elapsed since forming of the stoma have a great impact.

Modern medicine considers the patient holistically. This means interdependence between the sphere of biological, psychologi-

cal and social life of patient. Every disease, being dysfunction of a biological sphere causes disturbances in the other two. In particular, the negative consequences of cancer affect the integrity of the spheres of human life. Rectal cancer is often associated with the necessity to perform a permanent colostomy. Although the surgery completed the implementation of the stoma is necessary to save the life is too often perceived by the patient as “mutilation”. Negative emotions are present at the moment of the first appearance of distressing symptoms and worsen as a result of the diagnosis of cancer. Patients are afraid of the surgery complications associated with performing a colostomy and stoma itself [5, 6].

## FEAR FOR OWN HEALTH AND LIFE

It usually appears at the time of diagnostic tests and certainly when the patient is presented inauspicious diagnosis. In the mental sphere there is a feeling of anxiety in patient with rectal cancer. This fear is largely relates to concerns about your own health or life. It is associated not only with the physical ailments, i.e. pain or identifying stoma by patients as a source of bad odors due to loss of control of the passing of gases and feces. Every disease, particularly cancer causes great fear. In patient’s mind there are questions like: Will I live? Will I suffer? Do I have time to sort out important things in my life? Often concern is addressed to the loss of dignity or social status. Very often anxiety is related to fear of dealing with self-care at appropriate level. Diagnosis of cancer is very large psychological burden in patients who, for example, are the only source of income for the family or single parent having a young child. It is a special situation for them. The question arises: How in this situation do? What will happen now with my child? Where will we get the money to live on? Just a person being in such family situations are the most vulnerable to the appearance of negative psychopathologic states, such as low mood or depression [7].

## LONELINESS, LACK OF SUPPORT

This is a serious problem for patients with colostomy. Staying in the hospital, often combined with chemotherapy or radiotherapy, makes it contributes to the prevalence of depression in this group of patients. The time of staying in the ward itself causes a certain degree of social isolation. The current way of life is disturbed, sometimes from day to day from the moment of diagnosis of rectal cancer. Contact with the closest family members and friends is limited. In addition, the hospital conditions are not conducive to strengthening family ties. Patients are often irritable, feeling sadness, grief because of their health.

Often 'discharge voltage' associated with an ongoing pathological process lies with family members or medical personnel. Such patient is characterized by anxiety, rudeness, aggressiveness, dryness and pessimism. This condition is sometimes contributed to periodically reduced contact with patient or coldness of loved ones. After performing a colostomy the causes of the above conditions are slightly different. Often patient harbored all the negative emotions and sensations and becomes introverted person, reluctant to contacts with other people. Colostomy is taboo for patients, their family and friends. In addition, the feeling of shame because of 'artificial anus', especially when the patient does not know any person with a stoma, increases his/her isolation. No support is primarily due to an incorrect perception by the family, loved ones and even the medical staff as well as lack of support that is expected by patient. The basis for optimal support is a conversation, when proper communication is disturbed [8–10].

## SOCIAL ISOLATION

It usually begins at the moment of becoming the necessity to undergo surgery when performing a colostomy will be the end result. The patient usually feels the fear and shame of admitting to the functioning with 'artificial anus'. This is a particular problem when another person with a stoma does not exist in the patient's environment. The patient is afraid of how will react his/her relatives, friends, colleagues or neighbors. Patient often assumes in advance that he/she will not be accepted in the current environments. Worrying appears about whether the disease, that patient fights with it, does not take away his/her capacity to serve former social roles. Anxiety is related to disturbing his/her own functioning, feeling of being independent of the others. Upon creation of stoma problems arise with its existence alone and care, growing especially after discharge from the hospital, when the patient is responsible for its care adequate dressing. It leads very often to limit social contacts due to the appearance of various types of fears. The fear of that the family will not accept the changed lifestyle, daily activities is significant problem. Patients embarrassed to odor emerging from stoma bags or sound of gases and feces excreted, which they are not able to control. They prefer to remain alone, they avoid to go to the distant family and friends. The religious sphere is important aspect for the elderly. Because of these embarrassing complaints they often refrain from going to Sunday Mass. Younger patients are ashamed to live with a colostomy. They fear of that others will see ostomy appliance under clothing, what can be a reason of rejection or excessive interest. They are afraid of detaching of ostomy appliance which is associated with the soiling of body of clothes. It is

one of the biggest barriers significantly hampers social contacts [11–13].

## PROBLEMS IN THE SEXUAL SPHERE

There is fear of the new situation in most people who have colostomy. This concern relates primarily to the loss of sexual attractiveness. Image of their body is changed, i.e. the way of perception of one's body. Colostomy, although made in order to save the patient's life is still perceived as mutilation. Patients are often convinced that they cannot reach the full satisfaction with sex life no longer and that their partner also will not feel satisfied. Despite the many concerns related to this sphere, patients are ashamed to ask doctors or nurses about intimate contacts. The big problem for patients with stoma and their partners is to talk about intercourse, fears that it concern them. Partner often treat stoma as a taboo subject, they afraid that talking about it will bring psychological pain and unwanted emotions. This approach dismisses these people from one another, thus making difficult to get through a difficult moment, which is the act of sexual intercourse after surgery. Concerns accompanying the patient is primarily a fear of the unknown and new situations, unfavorable changes in bodily functions to perform sexual activity. Patients are afraid that during sex will occur feeling of pain or damage to the stoma. It is rather the vision of odor or detaching an ostomy pouch, which will soiling themselves, their partners, bedding, etc. In women with a stoma there is also the fear of pregnancy. They often do not know whether a pregnancy is not contraindicated in their situation and whether contraceptives, which have so far applied are still just as effective as in the past. Ignorance concerning these issues has a great importance in the development of sexual problems. It is worth noting that the emergence of any problem during the first intercourse after a colostomy often results in a reluctance to make further attempts. Such problems as the inability to achieve and maintain an erection, pain during intercourse often are transient in their nature but patients do not know about it [14].

## THE FEAR OF THE ONSET OF COMPLICATIONS OF COLOSTOMY

Surgery itself is associated with the risk of negative consequences. They may be intraoperative or postoperative complications. For those in whom surgery ending to form a colostomy is performed the possibility of complications from colostomy is particularly important. Prior to surgery, patients are informed about the possible negative consequences of the surgery. Often the names of complications tell little to patient, and a large num-

ber of new messages causes disorientation and confusion of the patient. Unknown medical terminology arouses anxiety in these patients, and the lack of explanation from the doctors or nurses intensifies it. This is a scheme of "vicious circle", leading to the accumulation of negative emotions. It is worth to note that the stoma complications may be caused by: improper performance of a colostomy, selecting the wrong place for stoma or wrong proceeding with the stoma. Early complications include: swelling; stoma ischemia resulting in necrosis and sometimes its pulling or retraction. Bleeding from the stoma and its infection are other early complications. Peristomal fistula or obstruction of the colostomy may also occur.

Late complications of colostomy include: stoma prolapse, twisted bowel, cancer recurrence in stoma. Other complications belonging to this group are the wrong location and a colostomy formed after irrigation, fistulae and bleeding. No wonder that the fear of the onset of complications of colostomy is such a big problem for patients with stoma. This happens mainly when the patient's doubts concerning these negative consequences are not explained up to date. A major factor in exacerbating anxiety is getting information from the Internet, especially from forums and other websites operated by laymen in the field of medicine. Then, descriptions of certain complications are often exaggerated or information are completely inconsistent with the current state of scientific knowledge on the topic [15].

## FEAR OF CARE AND LACK OF PROPER SELF-CARE SKILLS

Intestinal stoma is a source of the fear of its care for large group of patients. The idea that it is the intestine opening paralyzed patients before touching colostomy during care. Many patients fear that stoma may be easily damaged, that they can cause bleeding or stoma prolapse. This is a considerable problem, due to the fact that it adversely affects the ability to self-care of that person itself. Often nurses learning the proper care of colostomy indicate complications such as 'inability to take care of'. This is also a positive effect because it causes the attitude of responsibility for patients own health. On the other hand, it can trigger the fear of making a self-care of stoma. Patients fear that lack of experience and skills can cause complications. Most often, dermatological complications are negative consequences of improper self-care. There are dermatitis caused by intestinal content or allergic dermatitis. In turn, these changes may be infected, which determines the formation of bacterial or fungal infection [15]. Performing a colostomy in cancer of the rectum is seen as an attempt to save or prolong a patient's life at the expense of mu-

tilation of the body. This belief is a huge problem, both physical and psychological for patients and their loved ones. The new situation limiting current psychosocial functioning to some extent is the difficulty to accept it and forces patients to reorganize their lifestyle. Important elements in the process of accelerating or inhibiting an early adaptation to the new situation may be socio-demographic factors, as well as the process of treatment, checkups and recovery. Early acceptance of illness and satisfaction with life can be indicators of the quality of life of patients with colostomy performed for rectal cancer [16].

## THE ROLE OF THE STOMA NURSE

Stoma nurse next to her tasks related to stoma care, defecation and diet helps her patients to find themselves again and return to an active social and professional life. To make this possible the patient must accept the stoma and must get used to the daily fixing the bag. Stoma nurse should tactfully explain to the patient that the stoma is the price of saving lives. She must treat each patient individually, get in touch with him/her and gain his/her trust, she must have a time to talk, to listen and resolve patient concerns and ensure that patient can always count on her help. She should also educate patient that he/she is not alone and that many people live with a similar problem. It will be good if she will indicate a public person who has a stoma and live actively. To help the patient find themselves in a new situation stoma nurse should identify the place or person where the patient can find support. This can be a support group, where patients with stoma meet together and they can turn for help to a psychologist, talk with other patients with similar problems. Nurse may provide a phone number to the volunteers who care for patients with a stoma, if possible. Brochures, leaflets, magazines, websites for patients with a stoma are very helpful. Patients can find there tips on care, ways of solving psychosocial problems, news about an useful appliance and the experience of people living with a stoma [17–19].

Adapting to everyday life and acceptance in a family environment are key issues for the patient with a stoma. Think about how society accepts his/her illness overwhelms the patient. That is why the acceptance and support of loved ones have such great importance. There is a saying that time 'heals all wounds', this also works in the case of patients with a stoma in their favor. The patient gets used to stoma over time. Stoma nurse seeing difficulties in adapting the stoma should verify pessimistic thoughts about the self, develop a sense of responsibility from minor to major issues and strengthen a sense of independence. The patient even at the time to return home after the procedure should

feel confident in the field of stoma care itself. If despite all stoma nurse's efforts and the support and help from family during a year the patient did not accept the stoma, it is probability that he/she requires professional counseling [18–21]. Otherwise, if the patient cope with the care of the stoma and daily routines and he/she has no problem with them, then the task of stoma nurse is to encourage patients to take active and return to social life, working life, to practice their favorite sport, provided that they do not require heavy physical exertion [17, 22, 23].

A major problem in these patients is the lack of use of psychological consultation, as well as help from support groups. The lack of counseling increases the length of time to adapt to the new situation and to reduce the level of life satisfaction. This could be due to a lack of such need, lack of information on this topic or access to benefits. For these patients a good quality of life is associated inter alia with the acceptance of the stoma. Knowledge of these relationships allows us to understand their needs and often change our behavior in this regard.

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**Authors' contributions:**  
Andrzej Nowicki: 80%  
Paulina Farbicka: 20%.