



Understanding the needs of cancer patients in the Czech Republic

Mgr. et Mgr. Anna Rubešová, Ph.D. – Amelie, z.s.

Bc. Michaela Čadková Svejková – Amelie, z.s.

Mgr. Zita Dubová – sociologist in market research

Summary

Psychosocial care provided to people with cancer improves quality of their lives and reduces treatment costs. A survey, the first of its kind in the Czech Republic, was conducted to identify psychosocial needs of cancer patients and evaluate their perceived importance. In order to explore the needs we have created a questionnaire, which was completed by 253 respondents. Responses showed that patients with cancer place high importance on good relationship with healthcare professionals, psychological support and information regarding what state support they are entitled to during and after the disease. In all these areas, care of cancer patients can be improved.

Keywords

Psychosocial care, oncology patients, psychosocial needs

Introduction

Oncological disease affects all aspects of life. Therefore its treatment requires multidisciplinary approach which includes psychosocial care, as the European guide for quality national cancer control programmes confirms (1). Psychosocial care reduces cost of cancer treatment. At the same time, it reduces patient discomfort and improves quality of life (2).

For psychosocial care to be effective, we first need to identify psychosocial needs of patients. Our survey aimed to fulfil that objective. Its findings can help professionals see opportunities for improvement of services provided to cancer patients and their families.

A need is an inner strength that determines how we respond to objects or situations that surround us. It is a situation of lack (or surplus) of something and it motivates our behaviour.

Abraham Maslow outlined a hierarchy of needs, with physiological needs at the bottom and self-actualization at the top (3). Oncological diagnosis affects all aspects of patient's life, including his social environment, and threatens needs fulfilment at every level.

At the basic level of Maslow's model are physiological needs necessary for survival such as the need to eat, drink and breathe. As any other serious illness, cancer may threaten fulfilment of even those basic needs. While the 5-year survival rate applies to ever-higher percentage of people with most common cancer types (4), many people still perceive cancer diagnosis as a death sentence.

The next level up contains security and safety needs, e.g. safe environment, material security, stability and order. Serious illness raises fear, anxiety and insecurity and presents danger of losing control, of changes in lifestyle and perspectives. To fulfil the need of safety and to maintain emotional stability the patient needs to cope with the fear that accompanies the diagnosis. Patients also need to feel that they have control over their life, and they need to cultivate hope, trust and positive outlook on the future (5).

The third level of the needs hierarchy includes belongingness needs such as intimate relationships, family, love, and being part of a social group. Cancer has impact on interpersonal relationships and sexuality and may lead to feelings of social isolation (6). If the need of belongingness is not met, it may result in loneliness, alienation or even depression.

The fourth level contains esteem needs which include status, self-respect and respect from others. Illness can result in feelings of inadequacy, unworthiness and dependence or in changes in family or social roles. Patients also fear social rejection, for example due to their altered physical appearance (7).

The top level belongs to self-actualization, i.e. the need to grow and realize personal potential. Illness brings about confrontation with existential questions about life and death. People may find comfort in various philosophical, spiritual or religious systems that may offer acceptable explanation and meaning of life and death. By definition, the need of self-actualization can only be fulfilled by each individual. However, professionals (psychologists, psychotherapists, or even doctors and nurses) may support the patient in his or her own self-actualization process. Thus the experience of having cancer may present an opportunity for personal growth (8).

Methodology

Qualitative research – interviews with patients

Our survey had qualitative and quantitative parts. The objective of its qualitative part – 8 in-depth interviews – was to identify frequently mentioned psychosocial needs of cancer patients to obtain a basis for preparation of the “Questionnaire mapping the needs of cancer patients”. Respondents for in-depth interviews were selected to represent the population of cancer patients.¹ The framework scenario of the interview was designed to map the needs appearing from the moment of cancer diagnosis to present.

Quantitative research – questionnaire

Quantitative part aimed to identify the importance of psychosocial needs from the viewpoint of cancer patients. Based on the outcomes of the interviews and experiences with the needs of the Amelie clients, the “Questionnaire mapping the needs of cancer patients” was created and distributed in electronic form among respondents through patient associations and other organisations and individuals.

The questionnaire examined the importance of 36 needs divided into three categories: 1) psychological needs, 2) needs related to social, legal and financial issues, and 3) needs related to healthcare. Respondents answered the question “To what extent were the following needs important to you?” and rated the needs on the scale from 1 (“the need had no importance for me” to 6 (“the need was very important for me”).

In total, 253 respondents filled in the questionnaire – 87% women and 12% men between 22-83 years of age (the average age was 55). At the time of our survey, 21% of respondents were undergoing oncology treatment and 79% were not currently being treated.



¹ Five women and 3 men with the following diagnoses: breast cancer (3), colon cancer (2), brain cancer (1), myeloma (1), hemato-oncological disease (1).

Our sample of respondents is not representative of the entire cancer patient population in the Czech Republic. The majority of respondents were women with breast cancer (54%); other groups of cancer patients had only marginal representation.² This reflects the fact that women with breast cancer are the most easily approached group, thanks to existing patient associations. It would be beneficial to search for the ways to approach other cancer patients and map their needs.

Results

Outcomes of the interviews analysis

The interviews showed that cancer patients' needs can be divided into three categories: psychological needs, needs related to social, legal and financial issues, and needs related to healthcare. Originally we did not intend to include the needs related to healthcare as this area is outside the limits of services provided by Amelie, z.s. However, the interviews proved that those needs are very important and therefore we decided to include them in the questionnaire.

Respondents spontaneously expressed their opinion concerning possible cause of their illness. They repeatedly said that their cancer was probably related to their previous hectic way of life and long-term stress. Example: *"I led a very hectic life. I had two jobs and ran from one to the other. Plus the family, a husband and two children – it was very stressful."* The other finding of the interviews showed that experiences vary depending on the stage of the illness. Respondents stated that help – professional support as well as help from their loved ones – is usually most intense during the initial stages of diagnosis and treatment but is lacking in the post-treatment period. While the person is perceived to be healthy, he or she is still recovering from the consequences of cancer and its treatment. People are often surprised by the fact that probably the most difficult period comes at the moment when they and their loved ones think that "the worst is over".

Importance of needs

We arranged the needs according to their perceived importance using "Top 2 Box Score", i.e. percentage of respondents who gave the need one of the two highest ratings on the scale (5 or 6). Table 1 presents the results. The needs related to healthcare were considered as most important by our respondents, occupying the top 8 positions on the list. The most important needs concerned the relationship between the patient and his/her doctor. Respondents need to trust their doctor. They also need the healthcare personnel to show human approach, explain possible negative consequences of treatment to them, and provide them with sufficient and adequate information concerning the illness, examinations and treatment.

Among the psychological needs, the most important ones included the need to have hope, optimism and strength to fight, followed by the need to have psychological support while waiting for the diagnosis and the need to have an opportunity to discuss one's feelings and fears.

The most important needs related to social, legal and financial issues included the need to have enough information on what the patient is entitled to, especially in the period after treatment. Above all, respond-

² The second most common diagnoses was gynaecological cancer (13%) followed by colorectal cancer (11%).



ents need information concerning convalescence (e.g. rehabilitation, medical spa stays) and other services and aids (e.g. compensation aids, ambulance, travel expenses covered by insurance). Financial aspects of cancer and its consequences are important as well – people are concerned about financial security for themselves and their family and need to know what support they can get (e.g. financial assistance, benefits, disability pension).

Importance of needs for individual groups of respondents

Significance of the difference in the importance of needs for individual respondent groups (women vs. men, people undergoing treatment vs. people who were not currently being treated) was calculated at 95% significance level. Women are indisputably more sensitive to the needs than men. 27 out of 36 needs were perceived as more important by women than by men. The needs that were perceived with the same importance by men and women dealt with dignity and self-sufficiency.³ Therefore such needs can be considered as specifically important for men.

The findings also showed that some needs were more important for the people undergoing the treatment at the time of the survey, compared to those who were not being treated at the time. Namely this applied to the following needs: “help with ‘final arrangements’ (e.g. writing a will)”; “psychological support available also to my family/loved ones (e.g. from a psychologist or from friends)”; and “help with accepting changes in my body caused by cancer and its treatment”.

Discussion

Professional care provided to cancer patients focuses primarily on fulfilment of needs at the basic level of Maslow’s hierarchy, i.e. the needs that are necessary for survival. Yet the patients have many other needs belonging to every level of the hierarchy described in the Introduction.

Communication between healthcare professionals (HCPs) and patients

Regarding the high importance rating of the needs related to healthcare we can say that patients see their illness primarily through the prism of healthcare and only subsequently see its other aspects. Patients need

³ The approach of healthcare personnel to me should be human and personal.
Healthcare professionals (HCPs) should explain possible negative side effects and consequences of treatment fully, clearly and in due time.

To be an equal partner for the HCPs; to be able to participate in deciding on further course of treatment.

Not to be forced to wait for too long before the doctor can see me.

To maintain the feeling that I still have control over my life, that I can manage and that I can look after myself.

To have an opportunity to use the time spent in hospital in some meaningful way.

To receive help with accepting changes in my body caused by cancer and its treatment (e.g. changes in appearance, pains, swelling, decreased physical skills).

especially good relationship and good communication with HCPs. Good communication between the patients and their doctors has impact on the quality of treatment – patients are more satisfied with their treatment, more willing to share sensitive information, and more likely to follow advice (9). Patients who believe that their HCP is interested in their situation are also more willing to admit that they use alternative and complementary treatment. Such treatment is commonly used by cancer patients (more than 50 percent adopt alternative therapies) and healthcare providers fear possible interactions with conventional care (10). A patient-oriented approach results in increased resilience, i.e. patient's ability to adapt and live with chronic disease (11). The above-mentioned data suggest that it would be beneficial to encourage doctors to improve their communication skills (12).

Psychological support for cancer patients

As concerns psychological needs, we can conclude that the most important needs according to our respondents are psychological support and an opportunity to discuss and share their experiences. Ample evidence suggests that cancer patients experience significant level of emotional distress. It is estimated that approximately 20% of cancer patients suffer from depression or anxiety in some stage of their illness (2). Regrettably, psychological support does not constitute an integral part of care commonly provided to cancer patients at present.

Psychosocial needs in post-treatment period

Once cancer treatment ends, people have to return to their ordinary lives, and often to work as well. Experiences of the Amelie clients show that people often feel under pressure as the others (their employer, family and friends) expect that they will be able to return to their previous level of performance. Even patients themselves often have unrealistically high expectations concerning the speed of recovery and are taken by surprise when their health problems and negative emotions continue. Moreover, they lose the social support network that was created during their treatment, and instead of feeling happy that the treatment is over they often feel worried, lonely and weak. They have to cope with limited abilities, sometimes combined with the need to change jobs or redefine their roles in the family – and deal with all this at the time when they feel weak both physically and mentally. Post-treatment period (approx. up to 2 years after being diagnosed) can be described as a “period of return” during which “cancer patients” change into “cancer survivors” (13).

The majority of available research on psychosocial aspects of cancer focuses on the stages of diagnosis and treatment. Considering the increase in number of cancer survivors we can only welcome the fact that more attention is now being paid to post-treatment stages (13).

Differences in perceived importance of needs by men and women

Psychosocial needs are perceived as more important by women than by men, which only confirms previous findings. Gender was found to be the most important factor influencing the importance of cancer patient needs – more important than diagnosis, age, education or stage of cancer (14).

Women also sooner than men seek help in case of mental problems related to somatic illness (15). Unlike

men, women expect that they will be provided with both information and emotional support by healthcare personnel. Men tend to consider emotional support provided by healthcare personnel as inappropriate and to better cope with their illness, they prefer to receive information (16). Social norms dictate that it is more “acceptable” for women to talk about their needs and seek help with their fulfilment. It is less clear what support men need to fulfil their psychosocial needs. Our survey confirms that needs that are specifically important to men are related to the feelings of dignity and self-sufficiency. It is possible that men, by comparison to women, have a stronger tendency to “manage” their illness themselves and perceive support seeking as a sign of weakness.

Stressed by stress

At present, general public is well aware that stress has negative effects on health. In qualitative part of our survey the respondents pointed out the link between their illness and the level of stress they had been under. We have the same experience from our work with clients at Amelie, z.s. People repeatedly express concerns that stress will have negative impact on their illness progression. Ironically, health education for the public on stress management may have resulted in additional stress factor: “stress caused by awareness of stress”. Patients find themselves in a situation that is by definition stressful in many aspects but at the same time they strongly feel that stress will worsen their condition and they feel guilty that they are unable to stop feeling stressed. Recent surveys suggest that people who believe that stress is bad for them show increased somatic symptoms. Negative belief about stress thus becomes more important than our real situation, however stressful it may be (17) (18).



Table 1: Needs in order from the most important to the least important

Type of need ¹	Need ²	Percentage of respondents for whom the need was important ³		
		Total	Women	Men
Z	• To be able to trust the doctor.	90%	91%	81%
Z	• Human approach of healthcare personnel to me.	90%	90%	87%
Z	• Adequate explanation of possible consequences of the treatment.	88%	88%	84%
Z	• Adequate information from healthcare professionals (HCPs) concerning the illness, examinations and treatment.	87%	91%	58%
Z	• The doctor should have enough time for me.	87%	90%	65%
Z	• HCPs should help me overcome the consequences of treatment.	83%	86%	65%
Z	• To be an equal partner for the HCPs.	77%	78%	71%
Z	• The doctor should be willing to fill out forms and confirmations.	76%	79%	58%
P	• To have enough hope, optimism and strength to fight.	72%	75%	55%
Z	• Not to be forced to wait for too long before the doctor can see me.	71%	71%	68%
P	• To have psychological support while waiting for diagnosis.	69%	72%	45%
P	• To have a chance to discuss my feelings and my fears.	69%	73%	42%
S	• To have a chance to gradually return to normal life.	66%	69%	48%
S	• To get information on convalescence.	65%	68%	42%
P	• Discussions with people who are in a situation similar to mine.	65%	67%	45%
S	• To obtain information on what I am entitled to in relation to my illness.	64%	66%	52%
S	• To obtain information on how to provide financial security for myself and my family.	61%	63%	48%
Z	• Enough chairs in waiting rooms.	61%	63%	48%
P	• To feel that I still have control over my life.	61%	61%	58%
P	• To receive support with accepting my diagnosis.	60%	63%	39%
P	• Despite the illness, to feel that I am still needed and can help others.	60%	62%	48%
Z	• The HCP should provide me with contacts to other support available to patients.	60%	62%	42%
P	• To receive support with accepting changes related to illness (e.g. being unable to work)	52%	54%	35%
Z	• Support with meaningful ways to use the time spent in hospital.	51%	50%	58%
P	• Help with accepting changes in my body.	50%	50%	52%
P	• Not to feel like other people avoid me because of my illness.	50%	52%	32%
S	• To get information on how to arrange employment issues before treatment starts.	48%	51%	29%
S	• Advice on what to do when I have a disability but am not entitled to disability pension.	48%	50%	32%
S	• To have transport or someone to accompany me to examinations or treatment.	48%	51%	26%
P	• My family/loved ones should also get psychological support.	43%	45%	29%
S	• Help with finding a suitable job after treatment.	39%	42%	19%
P	• Help with informing my loved ones about my diagnosis and all related issues.	38%	40%	23%
P	• To receive advice on how to deal with attention and memory problems that appeared after treatment.	36%	39%	13%
S	• Help with children or household chores during treatment.	33%	35%	16%
S	• Better access to social services.	26%	26%	23%
S	• Help with "final arrangements" (e.g. writing a will).	25%	26%	19%

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