

Michaela HARABIŠOVÁ

Matej Bel University in Banská Bystrica, Slovakia

e-mail: harabisova.m@seznam.cz

ETHICAL-NURSING APPROACH TO THE QUALITY OF PATIENT'S LIFE IN A TERMINAL STAGE OF THE CANCER DISEASE

Abstract. There are health issues that concern larger or smaller groups of people, but the topic of oncological diseases, which are one of the most urgent problems of human society, concerns us all. Oncological disease is an immense interference not only in the life of a person with the disease, but it is also a stigma of their whole family to a large extent. For all people involved, the situation becomes very demanding, especially when the disease enters the terminal stage. The quality of life of terminally ill cancer patients is determined by the degree of personal suffering and the ability of the patients to individually meet their various needs. Awareness of the profound aspectual essence of ethical and humanistic connections in the context of providing suitable nursing care, focused on the application of the most possible degree of empathy and loving approach to patients based on reverence and respect for human dignity to the end of life, contributes significantly to the improvement of the quality of life. The contribution also contains a survey focused on the quality of life of terminally ill cancer patients.

Keywords: Quality of life, Cancer disease, Terminal stage, Patient's needs, Nursing care, Ethical approach

ETYCZNO-PIELĘGNIARSKIE PODEJŚCIE DO JAKOŚCI ŻYCIA PACJENTA W KOŃCOWYM STADIUM CHOROBY NOWOTWOROWEJ

Streszczenie. Istnieją tematy medyczne, odnoszące się do większych lub mniejszych grup ludzi, lecz temat chorób onkologicznych (nowotworowych), które są jednym z najbardziej naglących i aktualnych problemów społeczeństwa, dotyczy nas wszystkich. Schorzenie onkologiczne przynosi głęboką ingerencję nie tylko w życie człowieka chorego na raka, ale w dużej mierze jest to piętno dla całej jego rodziny. Dla wszystkich zainteresowanych sytuacja staje się bardzo trudna przede wszystkim wtedy, gdy choroba wchodzi w końcowe stadium. Jakość życia osób nieuleczalnie chorych (onkologicznie) zależy od stopnia osobistego cierpienia i zdolności pacjenta do samodzielnego zaspokajania

zróżnicowanych potrzeb. Świadomość głębokiej esencjonalnej istoty powiązań etycznych i humanistycznych w kontekście zapewnienia odpowiedniej opieki pielęgniarstwa, skupiającej się na empatii i miłym podejściu do pacjentów, szacunku i poszanowaniu godności ludzkiej do końca życia. Przyczynia się to znacząco do poprawy jakości życia. Częścią pracy jest również badanie dotyczące jakości życia chorych w schyłkowej fazie choroby nowotworowej.

Słowa kluczowe: jakość życia, choroba onkologiczna (nowotworowa), stadium końcowe, potrzeby pacjenta, opieka pielęgniarstwa, etyczne podejście

Introduction

Oncological diseases are among the most urgent problems of human society. A look at the history of tumors shows that cancer diseases are not new diseases, but the new issue is their increasing numbers. It doesn't affect only the human race, but in fact all of the living matter (Koutecký, 2008, p. 202).

The first mention of this topic was made by the Greek doctor Hippocrates, who was the first person to use the term "carcinoma" (from the Greek "carcinos" = crayfish). It was probably the image of an advanced breast tumor what served Hippocrates as an inspiration, which, with its rays, was reminiscent of crab pincers. Ancient doctor Galen subsequently used the term "tumor" (tumor, from tum tumer = to swell) (Macounová, 2009, p. 4).

The significance of the severity of oncological diseases is nowadays in the context of the current warning of International Agency for Research on Cancer (IARC) - a specialized agency of World Health Organization (WHO), that global oncological burden is growing at a alarming rate. Although the incidence and mortality of children and adults have dropped in this scale, especially in countries with well-organized screening programs, the diagnosis of malignancies remains a serious intervention in human life balance, which not only brings fear of pain and death but also a number of problems in the biological, psychological, social and spiritual dimensions (Šafránková, 2006, p. 121).

The dimension of pure humanity declares perhaps no existing doubts as to the prospective necessity of deepening a understandable human approach in the context of a critical reflection of own and foreign attitudes, recognition of prejudices and desirable assumptions, with the utmost elimination of overlooking ethical aspects of the work of healthcare professionals in the care of oncologically ill patients in the terminal stage of the disease.

1. Quality of life

In his publication, Křivohlavý (2002, p. 162) states the idea of Dutch psychologist J. Bergsma, who wrote about quality of life: "Since people exist, they have always been able to think and think about their lives. The quality of life was not just the focus of their thinking. It was also the source of their inspiration - not just what they did, but also the changes to which this concept of life led".

The term "quality of life" has been the subject of human activity since time immemorial and occurs in various areas of human thinking. The term was introduced to psychology at the end of the 1930s by American psychologist Edward Lee Thorndike, in the medical profession the term entered in 1972 (Adam, 2011, p. 132).

We are used to talking about quantity, that is, the length of life that can simply be expressed by numbers. But what is its quality? This can not simply be expressed in this way, because quality, semantically expressed as "grade, value", is a subjective variable that can be generally defined as a subjective assessment of one's own life situation. Already Aristoteles said that happiness, and hence the quality of life, is different for every person: "When one gets sick, he sees happiness in health. When he's alright, the happiness for him is money." (Křivohlavý, 2002, p. 162).

The relationship definition says that the quality of life is a reflection of the disparity between the filled and unfulfilled needs and desires, the measurable definition then states that the quality of life measures physical, psychological, social and spiritual health (Adam, 2011, p. 134).

At the beginning of the new millennium, on 4 February 2000, the Paris for the World Summit Against Cancer was signed at the World Summit Against Cancer for The New Millennium, with the aim of involving governmental and non-governmental organizations in reducing the incidence of this disease, supporting research, supporting patients and improving the quality of life of cancer patients. Union for International Cancer Control (UICC) then announced this day, February the 4th as a World Cancer Day (World, 2017).

1.1. Quality of Life of A Patient in the Terminal Stage of the Disease

Quality of life in cancer patients represents a very important, although not unchangeable aspect. It changes over time in response to changes in the body of the patient and the reaction of their surroundings. It assumes particular importance, when the disease gets to its terminal stage.

The terminal stage of the disease generally presents with a situation when the ongoing pathological changes in the body are essentially irreversible, and therefore it is no longer

possible, or with respect to the patient's condition it does not make sense, to try to correct the incurred changes (Jedelská, 2007, p. 34).

Within the oncological diseases it is a specific clinical condition, when the dissemination, or locally advanced cancer disease, or associated complications result in an irreversible failure of one or more organ systems. Death is inevitable and expected ending of the overall condition within the timescale of hours, days, exceptionally weeks (Ševčík, 2010, p. 195). Javůrková with Raudenská (2011, p. 120) define this condition as the final stage of the disease when curative treatment has been completed. In the terminal stage it is important to alleviate problems, pain, provide the patient with psychological, respectively also spiritual assistance, if they so require.

As reported by Beran (2010, p. 111) the treatment of patients in the terminal stage of cancer disease includes pharmacotherapy with an important place in eliminating unwanted symptoms. But if we are to talk about an adequate ethical psychological level of care, the communication with the dying should not be limited only to this topic. Interest, listening, understanding and emotional support represent efficient therapeutic means.

Taking care of the needs of others is an essential goal of nursing and patient's advocacy constitutes its ethical rudiment. In context with the above-mentioned the emphasis must be placed on respect for and protection of patients by health professionals as well as on the increase of their mental well-being. If the patients do not regain health, the health professionals should be aware that they did everything to ease their dying and to ensure a peaceful death. The patients can make decisions regarding the needs for the care of their health and protecting and promoting their rights. It is necessary to accept the individual wishes of patients and their decisions regarding their health (Seal, 2007, p. 30).

In addition to medical and quality nursing care aimed at the elimination of suffering, pain and other symptoms accompanying cancer and conditioning the quality of life of the diseased, this group of patients requires professional ethical approach based on respect and human dignity.

If health professionals help the patients to cope with difficult situations stemming from the dead end nature of an oncological disease, it is not only an expression of their professional erudition, but above all their ethical maturity.

Our contribution also includes a survey of the opinions of cancer patient respondents on the quality of life in its varied dimensions.

2. Survey of dimensions of quality of life

If care for patients in the terminal stage of oncological disease is to be correct and ethical, it must be complete. We must think of human as a multidimensional being, with a fully

holistic and ethical attitude. Analysis of the quality of life of terminally ill patients is a very difficult topic and the result of very difficult and sensitive communication with patients who are in the terminal stage. It forms the essence of the survey that we conducted in 2011 within the Czech and Slovak Republics and which present here. Due to the constant prevalence of oncological diseases, we have tried to identify which factors affect the quality of life of patients in a positive or negative way, with the aim of looking at the patients' life situation, which ultimately can lead to a better understanding of it and thus to deepening the ethical understanding approach of nursing care.

2.1. Target

The main objective of the survey:

Find out how the patients in the terminal stage of cancer perceive their quality of life.

Secondary objectives of the survey:

1. Ensure patient's satisfaction with various dimensions of the quality of life.
2. Find out the patient's perspective of the quality of their present life.

2.2. Patients and methods

For the purpose of our research and in relation to its objectives we distributed a questionnaire to 100 respondents. 65 respondents completed the questionnaire, of which 43 were women (66.15%) and 22 men (33.85%). In the Czech Republic the questionnaire was completed by 46 respondents (70.76%) - patients of the hospice of St. Lucas in Ostrava - Výchovice and Hospice of Frýdek Místek. In Slovakia, there were 19 respondents (29.24%) - patients of the House of Mercy in Banská Bystrica and Oncological Department of the University Hospital of F. D. Roosevelt in Banská Bystrica.

(We realize that the above number of respondents is relatively low to draw relevant conclusions from the survey; on the other hand, given the complexity of the issues and the overall health condition of patients in the final stages of life, we respected when the patient refused to cooperate for the above reasons).

In connection with the most important demographic data of respondents we would like to note that the largest group of respondents was in the age range of 60-69 years, in the number of 16 (24.62%), 27 respondents (41.54%) were married, 18 respondents (27.69%) lived with the disease for one year, respectively from three to five years.

To acquire the significant information about how the patients in the terminal stage of cancer perceive their quality of life, we chose a non-standardized questionnaire consisting of 23 closed questions. Selection of respondents was deliberate. Its fundamental criterion was cancer in the terminal stage of disease.

Data collection was conducted during the period from 1st November 2011 to 14th December 2011. All respondents were informed of the objective of the questionnaire and also

of the method of its completion, i.e. in almost any question the respondents could choose one of the options as answers: *not at all*, *almost not*, *sometimes*, *rather yes*, *absolutely yes/always*.

The results of the responses to the questions in the questionnaire were processed quantitatively and evaluated in absolute numbers and percentages.

2.3. Results

The results of the responses to the questionnaire were divided into 4 main areas of focus of the individual question (see table 1, 2, 3 and 4).

Table 1

The respondents' answers to selected questions related to the biological needs, activities of everyday life and the most prevalent health problems

P.No.	Biological needs, activities, problems	Not at all	Rather not	Sometimes	Rather yes	Absolutely yes/always	Total %
1.	Need for assistance during normal self-care activities	21.54	21.54	7.69	18.46	30.77	100.00
2.	Need for frequent rest	9.23	16.92	13.85	29.23	30.77	100.00
3.	Satisfaction with motor activity	26.15	30.77	12.31	15.38	15.38	100.00
4.	Satisfaction with sleep	16.92	12.31	40.00	21.54	9.23	100.00
5.	Pain	9.23	12.31	36.92	29.23	12.31	100.00
6.	Respiratory problems (shortness of breath)	32.31	33.84	21.54	12.31	0	100.00
7.	Digestive disorders	4.62	27.69	26.15	30.77	10.77	100.00

The answers of the respondents clearly show that in connection with satisfying biological needs and activities of daily living almost 40% of terminally ill require assistance at everyday self-care activities and in 60% of them the health conditions causes greater need for rest. An important factor affecting the quality of life of respondents is pain.

Table 2

Respondents' answers to selected questions related to mental processes, capability of role performance in the family and leisure time activities

P.No.	Mental processes, role functions, interests	Not at all	Rather not	Sometimes	Rather yes	Absolutely yes/always	Total %
1.	Experiencing negative emotions	1.55	15.38	38.46	26.15	18.46	100.00
2.	Ability to concentrate	18.46	27.69	12.31	15.39	26.15	100.00

Cont. tab. 2

3.	Memorizing, remembering	30.77	27.69	9.23	32.31	0	100.00
4.	Limitation of role performance in the family	4.62	12.31	27.69	24.62	30.77	100.00
5.	Limitation of interests	6.15	13.85	20.00	20.00	40.00	100.00

Responses of more than half of the respondents (55.39%) show that health condition does not allow them to fully occupy their role functions in the family and 60% of the respondents were forced to significantly reduce their leisure time activities in connection with the disease.

Table 3

Respondents' answers to selected questions related to spirituality, to approach of health care workers (HCWs) and life values

P.No.	Spirituality, approach of the HCWs, assessing the quality of life	<i>Not at all</i>	<i>Rather not</i>	<i>Sometimes</i>	<i>Rather yes</i>	<i>Absolutely yes/always</i>	<i>Total %</i>
1.	Contact with a priest	23.08	10.77	7.69	29.23	29.23	100.00
2.	Adequate approach of HCWs	0	3.09	6.15	35.38	55.38	100.00
3.	Confidence of patients in HCWs	0	0	6.15	46.16	47.69	100.00
4.	Change in the value chain	0	0	7.69	53.85	38.46	100.00
5.	Quality of life is more important than its length	1.55	6.15	30.77	26.15	35.38	100.00

More than half of the respondents (58.46%) require contact with the priest and also state that quality of life is more important than its length (92.30%). Over 90% of respondents under the influence of the disease changed their value chain. Overwhelming majority of patients (90.76%) value the approach and express their trust (93.85%) in health care personnel.

Table 4

Respondents' answers to assess quality of life at present

		<i>Very bad</i>	<i>Bad</i>	<i>Satisfactory</i>	<i>Good</i>	<i>Very good</i>	<i>Total %</i>
1.	Evaluation of the quality of life at present	13.85	23.08	30.77	27.69	4.62	100.00

Table 4 shows that 67.70% of respondents rate the quality of life at present as very bad to satisfactory.

We can conclude from the survey results that after being diagnosed with cancer almost all respondents changed their scale of values. Age group did not play an important role in this issue. To the question regarding the present quality of life 30.77% of respondents answered with satisfactory option. This mainly relates to patients with cancer lasting less than one year. 60 (92.30%) of respondents considered the quality of life to be more important than its duration. The answer was such in respondents of all age groups.

It is apparent from the respondents' answers to questions related to their satisfaction in the different dimensions of the quality of life that almost all respondents suffer more or less intense pain, to a lesser extent they reported problems associated with breathlessness or indigestion. The respondents feel greatly limited by their poor physical condition, also in terms of their status in the family or leisure time activities.

We realize that the above number of respondents is relatively low to draw relevant conclusions from the survey. On the other hand, given the complexity of issues and the overall health condition of patients in the final stages of life we respected the fact that 35 of 100 interviewed patients refused to cooperate for the above reasons in completing the individual fields of the questionnaire.

2.4. Discussion

Due to difficult nature of the issues and the need for sensitive communication with terminally ill patients the possibility of comparing respondents' answers of our survey cohort with other research and survey studies only small. Available resources imply that the authors of similarly oriented works examined the quality of life of cancer patients, but in a relatively calm stage of the disease. The results are therefore different as in patients with advanced stage of the disease and due to the different character of the set they cannot be compared in the entirely relevant manner.

Despite this fact we present results of the survey conducted by IRBIS, which in the first quarter of 2001, in cooperation with the management of professional association of patients Arcus - Onco operating in the Czech Republic conducted a research on the quality of life of women with breast cancer. The survey addressed 700 women via a questionnaire, while the return of the questionnaire was 60%. The role of the respondents was to indicate the importance of the problems that they encountered in the course of treatment of cancer. The results of the survey are presented in the work of Brychta and Hnilica (Brychta, Hnilica, 2001, p.18).

The survey found that the biggest problem of women was fatigue, feeling of helplessness and anxiety, and in the third place it was pain. As opposed to that, the respondents of our group were most tormented by pain and limited physical condition in relation to leisure time

activities or the inability to adequately perform the role of life partner and parent in the family.

Almost the same conclusion emerged from the research on the quality of life of patients in palliative care conducted by Bc. Magdalena Sadovská in 2011 (Sadovská, 2011, p. 82). The research took place from January to February 2011 amongst 32 patients hospitalized in the Department of Palliative Care of the Internal Clinic of the National Cancer Institute in Bratislava.

The results of the research pointed out that the symptoms of advanced cancer, including pain and respiratory distress in terms of dyspnoea have no significant effect on quality of life of the diseased. However, other symptoms of the disease, such as a fast onset of fatigue and weakness affect the quality of life negatively.

The author explains this phenomenon in a medicamental, respectively other manner used to eliminate pain and difficult breathing, which is practically impossible with fatigue and weakness.

The research results published by Sadovská (Sadovská, 2011, p. 120) are comparable with the conclusions of our research, in which the respondents did not report respiratory problems in terms of dyspnea, but rather problems with poor physical condition, which can be put into some context with rapid fatigability and weakness.

The questionnaire unveiled an interesting difference in responses between the Slovak and Czech respondents, which is that respondents in Slovakia are more reconciled with the situation when oncological disease entered its final stage. We believe that the essential reason may also be stronger religious feeling of the respondents in Slovakia, which determines the process of coming to terms with death.

Conclusion

The dimension of ethical nursing care for a terminally ill patient is a very difficult issue. The perception of the issue of dying in terms of the ethics of principles can give rise to many controversial polemics on the way to answering the question "What is optimal for a given situation?" (Heřmanová, 2012, p. 165).

Self-reflection on the level of personal access of healthcare workers in providing care and trying to think about their emotions should lead to understanding and respecting the patient's territorial circuits that work in conjunction with personal empathy, ow witch the maximum extent has no clear manual. It requires, above all, a good will and love based on a personal altruistic perception and a deep understanding of the provision of nursing care as functionally uninsulated, permanent, and complementary in communication. From the point of view of

utilitarian thinking, the way to the greatest benefit for others is searching for well-being, profit, and vice versa, reducing of suffering and pain.

The quality of life of patients should become the basic criterion of care for terminal cancer patients. Nurses and other health care personnel should strive not only to satisfy the full range of patient needs, but also to create, in accordance with the ethical principles in health care, an atmosphere of trust, respect, reverence and preservation of human dignity until its natural end.

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