

PALLIATIVE CARE IN RUSSIA. THE INITIATIVES OF NATIONAL CANCER RESEARCH AND TREATMENT CENTER

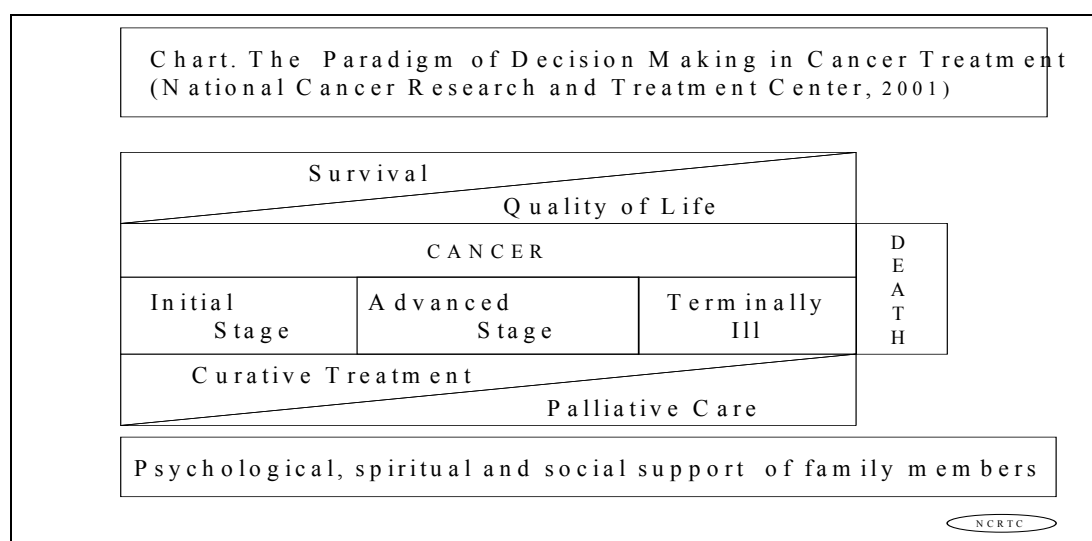
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The Russian Federation is the country with a high cancer morbidity, which unfortunately has a tendency to increase annually. For example, St.Petersburg, the second largest city in Russia (population of about 5 million people) has the highest cancer morbidity in Russia of more than 17 000 new patients per year. In Novosibirsk region, which covers a large territory of the Russian Federation, cancer morbidity comprises 333,5 per 100 000 citizens and has an annual increase of 5-6%. Moreover, the majority of patients are diagnosed with advanced disease.

However, the care of patients who need palliative treatment is far from perfect. It can be explained by a number of reasons. First, the lack of knowledge of the basic principles of palliation and deficiency of skilled specialists pose obstacles to creating a structure of palliative care in Russia. Second, there are the legislation limitations and the problems of drug use regulation. Moreover, evaluation of symptom severity and prevalence, its impact on quality of life and on adequacy of treatment as well as studies of the barriers to effective palliative care and symptom management are absolutely new in Russia. An extensive search of the current literature has found no citations describing the status of symptom control in cancer patients in Russia. However, based on studies that have been done in countries with more health resources, we can expect symptom prevalence and severity to be greater among Russian cancer patients than that found in such countries as U.S.A. and France. However, in the WHO-published data, narcotic drug consumption in Russia from 1994-1998 is significantly lower than in other European countries, and even lower than in Cuba and China. In addition, the WHO analgesic ladder is not the standard approach to pain management in Russia.

Due to this fact, one of the priorities of cancer health care system in Russia is to provide palliative and supportive care in accordance with the international standards. Taking into account the state-of-the-art of palliative care in the country the National Cancer Research and Treatment Center (NCRTC) (a non-governmental medical organization created in 1999 due to the initiative of clinicians, oncologists, researchers, and psychologists involved in the field of cancer diagnosis, treatment and research) has developed the paradigm of decision making in cancer treatment with palliative care as its important component. The sketchy description of the paradigm is presented on the chart.



The principle of balance of cancer treatment strategies is built into the above paradigm. Treatment strategies are determined by the treatment goals. These goals are as follows:

1. To cure + to improve quality of life (QoL)
2. To improve survival and QoL
3. To improve quality of life.

Combination of treatment goals might occur. For example, the goal of treatment of advanced cancer might be both to improve survival and to improve patient's QoL. Treatment approach is chosen depending on treatment goal(s). The goal and the approach are specified by the type and stage of cancer.

As it is seen from the chart, at the initial stages the first two goals dominate and the approach to be chosen is curative treatment. For terminally ill patients the major goal is to support QoL and in this case palliative treatment is the dominating approach. At the advanced stages combination of treatment goals and approaches takes place.

It is worth mentioning that palliative care of cancer patients starts from the early stages with its proportion increasing with the disease progression. It is important to stress that psychological, spiritual and social support of family members from the initial stages of the disease and after the patient's death is an inalienable paradigm component.

The compliance with the paradigm of decision making in cancer treatment should be supported by all the participants of decision making process: particularly by clinician who is in charge of patient treatment, Cancer Centers where a patient is being treated, and policy makers who are responsible for cancer care regulations. Thus, the paradigm gives grounds for the unified approach to cancer treatment.

Taking into account fundamentals of the paradigm, NCRTC has launched a long-term program to improve palliative and supportive care in the country.

The program includes the following milestones:

- Educational programs for specialists involved in palliative and hospice care;
- Introduction of pain assessment to provide adequate pain management;
- Introduction of symptom assessment to provide adequate symptom management;
- Implementation of quality of life assessment in palliative care in Russia;
- Training for patients and relatives to increase coping skills;
- Public awareness of the end-of-life care;
- Preparation of the initiatives on the protection of cancer patients rights;
- Support of non-governmental organizations in Russia involved in palliative and supportive care.

One of the recent projects of National Cancer Research and Treatment Center was Palliative Care National Education Program supported by the grant Open Society Institute.

The project lasted for 2 years and its major goals were as follows:

- To provide training for physicians, nurses, psychologists, social workers in different issues of palliative care from St.Petersburg and Leningrad region
- To provide training for physicians, nurses, psychologists, social workers in different issues of palliative care from different Russian cities
- To support home palliative care service on the basis of specialists prepared within the program
- To disseminate the education program on palliative care to different Russian regions.

The following results were achieved within this project:

- Educational program on palliative care has been developed. The program focuses on main aspects of palliative care and is available for dissemination and use for training in different palliative and hospice care settings;
- Educational materials (the booklet of 115 pages) including lectures on main topics on palliative care have been prepared and printed;
- Three educational cycles have been conducted:
 - Training for specialists from St. Petersburg and Leningrad region (Cycle One).
Cycle One consisted of separate courses for physicians and nurses and combined workshop:
 - Four workshops for physicians,
 - Four workshops for nurses,
 - One combined workshop for all participants of training;
 - Training for specialists from different regions of Russia (Cycle Two)
Cycle Two consisted of five workshops for physicians.
 - Training for specialists from St. Petersburg and Leningrad region (Cycle Three):
Cycle Three consisted of five workshops for hospice physicians, nurses and psychologists;
- Specialists involved in home hospice care have been trained within the educational program;
- Network of palliative and hospice care specialists from different Russian regions has been created;
- Information support to palliative and hospice care specialists within the network has been provided;
- Educational materials might be used in different sites of Russia for establishment and conducting educational program in palliative care.

The project start was the conference "Concept and Strategies of Palliative Care".

The conference was conducted as an introduction to the whole project. The conference achieved the following aims:

- During the discussions within the conference the most up-to-date- topics of palliative care for Russia were identified;
- Specialists from different sites of Russia participated and showed their need for the training
- Prof. Ch. Cleeland (M.D. Anderson Cancer Center, Houston, USA) participated in the conference and initiated on-going discussions on different aspects of palliative care (namely, pain control, symptom assessment, pain management in children, care of dying etc.) between the network members within the project.

The topics covered within the conference:

- Historical background of palliative care
- Modern concept of palliative care
- Strategies to pain management
- Organization of palliative care system in Canada
- Palliative care perspective in Russia
- Attitude to the dying in international community.

Specialists from the following types of institutions of Russia participated in the conference:

- Research institutes
- Regional oncological center
- Oncological hospitals
- Hospices
- Higher medical schools, universities, medical colleges.

The following groups of specialists took part in the meeting:

- Heads/chiefs of oncological hospitals, centers and departments
- Oncologists, chemotherapists, hematologists, general practitioners, anesthesiologists, radiologists
- Nurses
- Psychologists, social workers
- Medical students.

Representatives of 16 cities of Russia participated in the conference (Angarsk, Velikii Novgorod, Volgograd, Ekaterinburg, Ivanovo, Kirov, Moscow, Novosibirsk, Norilsk, Orenburg, Primorsk, Pyatigorsk, Saint-Petersburg, Sestroretsk, Smolensk, Yaroslavl').

As for the training courses more than 150 specialists have been trained within the duration of the project. Representatives from the 9 cities of Russia took part in the Cycle Two meant for different Russian regions (Moscow, Murmansk, Obninsk, Orenburg, Petrozavodsk, Severomorsk, Cheboksary, Chelyabinsk).

Educational program established in St. Petersburg as the model can be used in other Russian regions.

One of the ongoing projects within the program is the implementation of symptom assessment in palliative care in Russia. It is the joint project of NCRTC and Pain Research Group (PRG), M.D. Anderson Cancer Center (Houston, USA). The PRG which houses the World Health Organization's Collaborative Center for Supportive Care in Cancer, has a good history of international research collaborations that have resulted in validated new language versions of symptom assessment instruments and multi-site studies. These instruments have been implemented in clinical trials and clinical practice in various regions of Asia, Europe, and Latin America. The goals of the above project are as follows:

- To establish the validation of symptom assessment instruments (Russian versions of the Brief Pain Inventory, Brief Fatigue Inventory, M. D. Anderson Symptom Inventory);
- To search for the prevalence of pain, fatigue, and other cancer related symptoms among the cancer patients in the institutions affiliated with NCRTC;
- To examine the current status of adequacy of pain management and its barriers in Russia.

The first stage of the project was been successfully finalized.

Another important field of activity of National Cancer Research and Treatment Center is participation in conducting international conferences on cancer treatment and quality of life issues. In this connection it is worth mentioning two conferences which took place in St.Petersburg during the last two years: "Palliative Care and Quality of Life" (28-29 September, 2001) and regional meeting of the International Society for Quality of Life Research "Quality of Life Research in Medicine" (3-5 October, 2002). Within the latter conference there were the sessions covering palliative care issues and round-table discussion "Palliative Medicine: QoL Issues and Patients Rights".

In conclusion, realization of the program developed by National Cancer Research and Treatment Center will be a relevant contribution to the improvement of palliative care in Russia and its compliance with the international standards.

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