Carmen ANGHELUȚĂ, MD, Public Health Senior,
Carmen SASU, MD, Public Health Senior, Scientific Researcher,
Lavinia PANAIT, MD, Public Health Senior,
Teodora CIOLOMPEA, MD, Family Medicine Senior,
Georgeta POPOVICI, MD, Family Medicine Senior

1 National School of Public Health, Management and Professional Development, Bucharest

INTERNATIONAL CONTEXT

Oncology disease represents an important public health problem globally, making it one of the leading causes of morbidity and mortality in the world. Gravity of this problem is a majorone considering the fact that annually are diagnosed with neoplasm over 12 million people and recorded nearly 8 million deaths/year, estimates indicating that by 2030 the disease incidence will be 68% higher, while the number of deaths will reach about 13 million annually [1]. Oncological issue is even more dramatic in the poor countries of the world, the statistics showing that about 70% of cancer deaths recorded in 2008 occurred in low and middle income countries[2]. Although at european level, since 1994 there has been a slight decline in terms of mortality rates for all cancers, for both sexes, it is found that the exception to this model is made by economically less developed countries such those form Central and Eastern Europe (Bulgaria, Romania, Latvia, Lithuania, Poland), where mortality has remained at the same level between 1994 and 2008, or even increased. [3]. A significant proportion of these deaths could be prevented, taking into account that about 30% of cancer deaths are due to behavioural risk factors such as: obesity, diet deficient in fruits and vegetables, lack of movement/physical activity, consumption of alcohol and/or tobacco. [2]

The experience of other countries has shown that the approach of appropriate prevention and treatment strategies to focus both on prevention of disease by influencing and changing unhealthy behaviours among the general population, and on the adoption and development within the health systems of the countries of the multidisciplinary approaches, innovative models of care and guidance of patients can produce positive results in the fight against this disease.

The continuous preoccupation at the international level to improve the quality of oncologic care has led to the development of models of good practice with proven efficacy, such as "oncology nurse navigator". Given the current situation in Romania, in terms of morbidity and mortality through cancer, it is necessary the adoption and introduction of such innovative practice models, of great benefit to patients with cancer, but also for the health system. National School of Public Health, Management and Professional Development and Romanian Nursing Association meet this aim through the project "Innovative Strategy for Bridging Cancer Care in Romania" by elaboration of aninnovativemodel for oncology services in Romania. This model starts from the knowledge of the current situation regarding the barriers in the system, the needs of patients and medical staff and proposes the integration of the positive experiences in United States regarding the improving of early detection of the disease, improving the quality of patients' care and patients' satisfaction. The model of "nurse navigator" adapted, adequate for Romania is one of guidance, counselling, information and support for patients with oncological diseases, but at the same time, of education and prevention among the general population and population groups at higher risk for cancer.

MODELS OF GOOD PRACTICE REGARDING THE ONCOLOGY PATIENT COUNSELLING AND GUIDANCE-INTERNATIONAL EXPERIENCE

In order to develop the most advanced oncology services, in USA were created and developed innovative models of mentoring, counseling, support services for the cancer patient in the health care system, the "nurse navigator" or "patient navigator" models. Within them were well defined the roles of the cancer patient navigator, the types of services and care that the patient navigator can and should provide to the patient with cancer, facilitating him the access to all kind of oncological services available (diagnosis, treatment and recovery, of psychological counseling or palliative care services).

One of these, the "patient navigator" model was promoted by Dr. Freeman, being developed for persons belonging to the marginalized, impoverished communities. Dr. Harold Freeman, a recognized personality in the field of tackling cancer issues among the poor population from the United States, initiated in 1986 such a program by introducing people trained to facilitate access and tracking patients who had abnormal results on the screening test for breast cancer. The intervention involved the guidance of patients to access screening services and subsequent guidance for those who need the services towards diagnosis and treatment of breast cancer services.

The result of the intervention was positive, the rate of survival at 5 years of women diagnosed with breast cancer rising from 39% in 1986 to 70% in 2000, and the rate of diagnosis of the disease in the initial stages...
Patients to whom the “navigator” is addressed are not only the poor or not insured, but also patients who do not have sufficient knowledge about the early diagnosis, treatment and care options in Oncology, having obviously need for specialized advice. Mainly, the “Freeman model” considers that the guidance of the patient begins with the diagnostic phase and continues throughout the treatment. People who offer guidance to the patient can be nurses, social workers and other professions, however, they must have the knowledge and skills to enable effective communication with the patient, family and community, to empathize and to support the patient, to be familiar with the complexities of the health care system to be able to provide essential information to the patient. [4]

For such qualification there are organized many “patient navigator” training courses with a well-defined curriculum, the major goal being the acquisition of knowledge and skills in order to provide personalized care, starting from disease prevention till the end of patient’s life, thus facilitating its access in the system and removing barriers to obtaining timely screening, diagnosis, treatment, rehabilitation and support services. The Freeman Institute currently develops standards for the definition of the concept of “patient navigator”.[5]. The Freeman model is presented in figure 1.

Another example would be the model based on coping behaviour theories - British Columbia Patient Navigation that is based on Lazarus behaviour theory regarding stress. Within this model the accent is on supporting the patient that finding out the diagnosis of cancer passes through a critical phase of stress that need support and guidance. Once this stage is overcome is necessary to obtain trust and cooperation, so that the patient would adapt better to the new situation. Problems solving, cooperation, adaptation (coping) are basic elements of this model. Initially, it was considered that "the navigator"/guide should intervene limited, at the stage of diagnosis when the patient actually passes through a phase of intense stress and aims to support the overcome of the shock phase, for the patient to become cooperative and confident in the success of treatment. Further more this model also, recognizing that the discontinuities, and the system barriers can occur in all the patient pathway, starting with the stage of diagnosis, to to phase of treatment and intervention, requires the intervention of mentor/"navigator" in the oncologic and support services.

Figure 1: Patient referring for ensuring the continuing of care

Role of nurse/navigator
- Providing information
- Emotional support
- Facilitate the decision making
- Facilitate the connection with resources and health care
- Identification and development of communal support

Discontinuities form oncology services
- Initial diagnosis
- Integration within communal services
- Integration in paliative services

Expected results at patient level
- Improving the level of knowledge about the treatment and emotional preparation
- Increasing patient’s self-efficiency
- Increasing patient’s satisfaction related to medical services
- Decreasing the consumption of emergency and specialized services

Figure 2: Framework for oncology nursing navigator and care services

Source: British Columbia Navigation Model; From patient navigation: towards an Evidence- Based Psychosocial Model, retrieve from http://www.phsa.ca/Nr/rdonlyres

The needs of patient and family
- Presented by patient and family
- Identified by navigator

Faith and hope

Changing from emotion status
In problem solving

Social, communal support

QUALITY
The definition of the model started from the assessment of patients’ needs, the evaluation of existing best practices in the field of "guidance", the evaluation of models and theories, implemented in the US, and for the improvement of the concept the navigator's role has been defined on the basis of specific needs of the patient.[6] The model can be used for the development of complex services of oncology nursing, psycho-social factors being highlighted as key elements of specialized assistance.

The definition under this model of the patient's needs, of the issues in health services, as well as the definition of the nurse navigator’s role enable the organizing of the “navigation” service for patients. The model of the British Colombia Navigation is represented below in figure 2.

The model of patient navigation services offered by specialized nurse in Oncology as "oncology nurse navigator" brings a significant added value to the oncology services by using specialized persons in the field of Oncology. Clinical Oncology specialization by type of cancer and the availability of these resources right within the multidisciplinary oncological clinics make possible direct contact of a specialized nurse with the patient, even from the moment of suspected cancer, guiding him then in all the stages they go through the health care system.

According to the Academy of Oncology Nurse Navigators, oncology navigator nurse must have the necessary qualification to identify and remove barriers that appears in patient’s pathway in order to obtain timely and adequately specialized treatment. She guides the patient for the continuity of care starting with the diagnostic stage to the palliative treatment, to this aim coordinating all components involved in treatment (surgery, radiotherapy, medical services, social work, patient’s education, community support and financial assistance, insurance assistance, etc.). To achieve these tasks the nurse must have clinical experience and must be a member of the multidisciplinary team.

The effectiveness of the introduction of "nurse navigator" services in oncology has been demonstrated by favorable results obtained at the level of the patient, such as: increasing the adherence to therapy, reducing the time of diagnosis, reducing the waiting time for specialized treatments, reducing the number of scheduled visits to the doctor that have never took place by patient’s non-participation, increasing the number of presentations for screening exam, improving hydration of patients with chemotherapy etc. [7]

All these experiences and positive results are arguments in favour of the extension of such services that it has been demonstrated that can have positive influence on the level of the patient, on the evolution of the disease (early diagnosis, appropriate treatment in a timely manner, increasing compliance to treatment, etc.) and quality of life (by providing vital information to the patient by a specialized person), but also at the level of the health system by removing discontinuities in service delivery and also by reducing costs (e.g. diagnosis in early phases of the disease, be compatible with the survival but also to the reduction in treatment expenditures).

NATIONAL CONTEXT

For some less economically developed countries as Romania is, with insufficient budgetary amounts allocated to health, but with large enough values of cancer morbidity (275,46 new cases per 100,000 inhabitants compared with 397,94 new cases per 100,000 inhabitants, average in the European region, in the year 2010, according to the European Health for All Database) and values surpassing average values of mortality by this diseases in European region (180,1 deaths/100,000 inhabitants, standardised rate of mortality through cancer at all ages, in Romania in 2010, compared to the European average of 162,67 deaths per 100,000 inhabitants), [8] the solution to adapt such models of counseling and guidance to the needs of their own patients with oncologic disease can be one beneficial not only on individual plan, but also at the level of health services or for the community in which the patient belongs.

In order to improve the quality of oncology medical services, to facilitate the access of oncology patients to such services, the National School of Public Health, Management and Professional Development Bucharest, implements along with Romanian Nursing Association the project "Innovative Strategy for Bridging Cancer Care in Romania", funded by the Bristol Meyers Squibb Foundation, having as objective the elaboration of an innovative model of patients with cancer counselling and guidance.

The first phase of the project was the development of a needs assessment study, referring both to the needs felt by cancer patients from the time of diagnosis and throughout treatment, as well as to the needs felt by the health staff involved in cancer care, in an economical less-favoured region of Romania as it is region of South-West Oltenia. The obtained results were used as a material in discussions with health personnel skilled in the field of oncology nursing, on the drafting of a patient counselling and guidance model, adapted to the needs identified in our country and taking into account what exists as functional "oncology nurse navigator "or "patient navigator" models in other states.

NEEDS ASSESSMENT STUDY - MAIN RESULTS

Current situation analysis carried out in the project include: literature review (extent and severity of the phenomenon in terms of cancer morbidity and mortality, identification of best practice models in the field of oncology nurse or patient navigator), analysis of some indicators of hospital’s activity in the South-West Oltenia region (DRG data analysis, data reported by hospitals in 2011), qualitative and quantitative research methods (focus group with various categories of oncology medical staff in the region and questionnaires analysis distributed to staff and patients in hospitals in the region of Oltenia) to reveal the most significant aspects of the way that health services
meet the needs of oncological patient, which are the missing links in the system, which are the additional needs for care of those patients, frequent barriers on access to services, communication, information etc.

Specifically, the results of the research conducted in the field that have been taken into account for the elaboration of a counseling and guidance patient’s model have revealed the following:

A profile of cancer patient: patients coming from poor areas / disadvantaged region (especially from rural areas) represents the most of the cases, three quarters of the medical questioned staff thought that there is a correlation between lifestyle due to poverty and the occurrence with higher frequency of oncological diseases. The cancer patient from these areas has the following characteristics: submission to the doctor in the advanced phases of the disease, homecare is limited by financial shortages, there are difficulties in understanding the situation of disease due to poor education, these patients have financial restrictions on transport to treatment facilities or other expenses or have difficulty in following the correct treatment and diet and difficulty in obtaining the rights for people with disabilities.

Patients newly diagnosed with cancer need answers to basic questions such as: how they will survive, if and when there is pain, how much will cost the treatment, who treats them, what kind of lifestyle should adopt, where they can adress to, who can help? Often, at family’s desire in order to protect the patient from the shock of finding such a diagnosis, the medical staff doesn't informs the patient about his illness. Often, patients do not know their diagnosis and do not know what treatment they receive. The tendency to hide the disease to others, to the community, resignation, are factors that contribute to disorientation and lack of active involvement of the patient and family to achieve healing. Although the shock of finding out the diagnosis of cancer is dramatic, the awareness, involvement of the patient to obtain cooperation, adherence to treatment and support therapy, hygienic-dietary regime are necessary for the maximum effectiveness of therapy. In many cases, lack of family support is not matched by social and community support, so, especially the older people and the poors are the most vulnerable.

The basic information/knowledge of general population on cancer disease is appreciated by specialized medical personnel as being weak or at best medium for all aspects investigated: cancer risk factors, cancer prevention methods, signs and symptoms and the importance of presenting to the doctor. This means that a more active involvement of the various professional groups (medical staff, school-through health education classes, media, etc.) could lead to positive results in terms of better awareness of the general population of the danger posed by the disease and that presentation to the doctor in time can be lifesaving.

Problems in diagnosis and treatment are mainly encountered regarding cancer patients’ addressability. Mostly, patient goes to the state health system, to policlinics or hospital, and consequently is a need to improve some medical services provided this way, the most common being mentioned screening services, the palliative / end-stage care, home care services, laboratory and recovery services. The main reasons for this addressability are that patients are referred to those services by family doctors, but also the personal conviction that they will receive there the best medical care. In the field of cancer care setting up a therapeutic plan by an interdisciplinary team is very important, in the most of the cases the diagnosis is established by consulting a team, fact that is achieved spontaneously or organized according to a standardized procedure.

The support services need improvement. Among non-medical services that should be improved are especially specified those of counseling or public information activities on medical topics in order to increase the number of cases detected in the early stages of disease and services for people with disabilities provided by local authorities or services in community. Services as counseling cancer patients (on their treatment, lifestyle and healthcare guidance to easily access to prescribed services) although known to a relatively small number of respondents are considered useful, also is a training program for nurses (on the subject), that professional would help mostly by improving communication with the patient and his family, as well as by increasing confidence and patient adherence to treatment.

The most often encountered problems in the process of providing cancer care are represented by the insufficient diagnostic and treatment equipment, failures in the supply of drugs and the lack of integrated services for this particular type of patients and multidisciplinary teams involved in the process of diagnosis and treatment. Also as a problem is perceived the lack of participation in continuing professional development programs which enable updating of knowledge, according to medical progress.

Identified information needs of patients include: ways of patient information and guidance about his medical conditions and conduct to be followed, through medical staff or specialized persons that should provide patients and their families information about: patient’s disease, with all that entails it (nutrition, life style, treatment, possible complications, side effects of treatment), information about health units to which the patient may address by the type / stage of the cancer or about psychological/counseling services or other medical services, complementary, useful to patient, care in advanced stages of the disease, home care, etc.. Emerges also the need to provide information about the support that can be received into the community, from the town hall, church, various NGOs.

Conclusions
The complexity of the issues above highlights the missing links and obstacles in obtaining services that should be provided to patients with cancer. Of course, some reported problems such as lack of diagnostic and treatment equipment, lack of medicines, can be solved only
through the intervention of the competent fore (Ministry of Health, Health Insurance House), but other issues related to the territorial organization of services, the development of additional skills of medical and medico-social staff or hiring a dedicated staff to ensure the cancer patient’s access to adequate resources for diagnosis, treatment and care, so as to achieve better outcomes for health, physical and mental status of these patients.

Services as counseling and guidance for cancer patients to encourage patient and getting his confidence for acceptance and involvement in the therapeutic process, informing about the hygienic and dietary rules, guidance for an easier access to prescribed healthcare services, communication, specific knowledge update, health education and prevention services have been identified as highly needed by patients and caregivers in the research study. Taking into account the identified needs, services provided by such qualified nurse - navigator, advocate and educator of cancer patients can bring substantial benefits both to patients and health services system.

A MODEL OF COUNSELING AND GUIDANCE FOR CANCER PATIENTS ADAPTED FOR ROMANIA

In the context mentioned above, we consider a model of “nurse navigator” adapted, suitable for Romania would be one of guidance, counseling, information and support for patients with oncological diseases, but at the same time one of education and prevention among general population and groups at risk for cancer.

The current organization of medical oncology services would require substantial changes, such as better availability of diagnostic and treatment resources, the development of multidisciplinary teams, streamlining patient route. Also, legislative constraints related to staffing in health, require that the proposed model to develop on the base of the currently existing medical services and personnel employed in health services. Certainly, on the future, the introduction of specialist nurses dedicated to the role of "navigator" of the patient in medical oncology services with well-defined role and responsibilities, acting at different points of health services may be an important pillar of the organization of a multidisciplinary integrated medical oncology services to solve problems and remove barriers that are found in the present in the system.

Route followed by a patient from cancer suspicion to treatment, recovery and support services, is basically the way from the family doctor's office, where he is consulted and receives recommendations for exploration and analysis in hospital or center specialized in oncology. Typically follows hospitalization for surgery and postoperative treatment or there are directly prescribed various combinations of chemotherapy and radiotherapy at the hospital or ambulatory (Figure 3). Given the above conditions, for a future possible stage of piloting of patient navigator services is needed a development of the nurse’s skills at different levels of health care providers who act in the position that it is, as a patient navigator during the patient’s route in health system. It aims to create a network in which the nurses from community and oncology services to collaborate with professionals in health and social services in order to facilitate access and to support quality of care for patients with cancer.
As for the successful performance of the tasks incumbent, the navigator requires the development of specific skills. To the nurses that will have these roles must be given a special training program, aimed at increasing the ability to communicate, inform and support patients to access easier the health services, knowledge about psycho-emotional characteristics of oncological patients and methods to support overcoming the critical phases of stress of diagnosis, improving cancer care in various stages, educating patients on treatment compliance and adoption of hygienic-dietary regime, knowledge of the necessary support services, providing specialized care, its side effects, advice on diets, supporting in identification of vulnerable people and those at risk for cancer. In order to practice as nurse navigator, one person should know the organization of cancer care, the available services and options for treatment and care, regulations on how to access them, the responsible persons and decision makers in these services.

Within the health system, according to the health/medical services that nurse operates, its assigned specific roles, currently governed by various rules and regulations.

The proposed model adds new responsibilities and roles, depending on the level of care provided (primary, secondary/ambulatory, hospital or rehabilitation services) to meet the needs of a community or population of patients with cancer suffering.

Scheme of the navigator model proposed, with nurse navigator responsibilities is shown in Figure 4.

Currently the role of the family doctor's nurse or community nurse in care of the cancer patient is low, limited to some treatments. At this level, there is considerable potential for increasing the role in education of patients and population for cancer prevention, guidance for participation in screening programs, and also to meet needs of patients with neoplastic disease: guidance system, counseling, support, assessment.

In hospital and ambulatory practice the nurse is in direct contact with the patient, her role is primarily to provide a specialized treatment. At this level the nurse may intervene to guide patients to clinical investigations, providing psychological and emotional support, information on treatment and its side effects, advice on diets, supporting in identification of the necessary support services, providing specialized care, depending on the disease's stage or complication etc.

In summary, the recommended main responsibilities for nurse navigator are the following:

- Counseling and patient's support to access the oncology services required by his needs, scheduling meetings based on treatment plan established by a multidisciplinary team that treats the patient, discussion, psychological and emotional support to overcome stress occurred, obtaining the support of family or community.

- Developing collaborative relationships with physicians of various specialties, with other members of the multidisciplinary team to facilitate patient's appointments, conducting appropriate treatments, follow up the effects of treatment, coordination of care.

- Providing information needed for patient and family about illness, adverse effects of treatment, hygienic and dietary regimen, lifestyle, alternative treatments etc.

- Facilitating patient's communication with medical staff to obtain his adherence to the prescribed treatment.

- Facilitating patient communication with social services staff to more easily obtain the rights for people with disabilities.

- Provide a schedule (hours) of health education, prevention and early detection of neoplastic disease in the community.

Developing competencies represents the base for defining the role of nurse navigator for patient with cancer, which in future could become a specialized employee in oncolgy services in our country, with favorable results as in the case of other countries. As noted above, introduction of the model proposed in Romania (coordination services, care, guidance and counseling to cancer patients) is based not only on assessing the current status of services, with emphasis on needs identified among both patients and among health professionals involved in providing specialized services, but also on literature research to identify models of good practice and on consulting foreign experts in oncology nursing, practicing specific "nurse navigator" services in the U.S., with impressive results on patient level. Since in Romania this field of activity is new and practicing these activities requires legal accountability, cooperation, teamwork and coordination with other specialists, we consider it necessary to involve more doctors, oncoologists, decision makers in the healthcare system, hospital's managers, professionals from health and social services and representatives of local authorities and cults to improve and put in practice the proposed model. Involving all of these categories can create conditions for the cancer service’s quality improvement and especially can improve quality of life for cancer patients.

References:
   http://dx.doi.org/10.1787/health_glance-2010-en
   http://www.hpfreemanpni.org
5. PATTON, A.,-A conversation with Dr. Harold P. Freeman-Cancer Care patient Navigation- A Publication of the Association of Community Cancer Centers 2009;
7. GILBERT et al, -Nurses as patient navigators in cancer diagnostic: review, consultation and model design, European Journal of Cancer Care, 2011;
8. European Health for All Database; http://data.euro.who.int/hfadb/
   http://data.euro.who.int/hfadb/