

Joint Interactive Symposium ISNCC/EONS

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The charity approach experience

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The United Kingdom has benefitted from over 50 years of a National Health Service which for everyone is free at the point of delivery. Across the UK there are now over 600 cancer related voluntary organisations that are charitably funded. Macmillan Cancer Relief is one of the largest cancer care charities and since 1911 has worked to provide help and support to people affected by cancer. For some years cancer has been a top agenda item for the professionals, for the public and for politics. There have been unprecedented opportunities for partnerships to be developed across many interfaces but in particular, between the statutory sector (NHS) and voluntary /charitable organisations.

Macmillan is committed to the improvement and development of services for people affected by cancer. Through developing a wide range of services and posts Macmillan has been able to make a real difference. Examples include the Gold Standards Framework, which is a toolkit designed to help and support people who are reaching the end of their lives and who wish to remain at home rather than be admitted to hospital or a hospice. The importance of listening to cancer patients and ensuring their voices are heard cannot be underestimated and Macmillan is working in partnership with the NHS to establish facilitated groups across England which will provide training and support for cancer patients to take their place on planning, policy and strategy groups where cancer services are discussed and where plans are developed.

The charity approach to continuity of cancer care in UK is built on a foundation of independence. Cancer charities have freedom to be innovative, to seek partners across previously difficult interfaces – for example the private sector, industry and public sector organisations, and to utilise their significant experience and expertise in the shaping of national policy. Cancer charities may work alone or in federations or alliances. There are examples across the UK of significant improvements in policy, in NHS structures, in cancer treatment and cancer care where the charity approach has ensured the voice of the cancer patient is heard and services really do meet identified needs.

Cancer charities have had a vital role in maintaining the momentum of change within cancer services. As their body of knowledge expands and increases with the generous support of many hundreds and thousands of donors, so will their capacity to develop and deliver services and to influence the agendas across the country.

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A practical example of a multidisciplinary approach in continuity of care

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It is remarkable how many changes have taken place. At the beginning of 1989 only few people were able to anticipate the quick collapse of the former regimes in Central and Eastern Europe. Pulling down of the Berlin wall with all its symbolism is closely related, both politically and economically, with our heading to European Union.

Masaryk Memorial Cancer Institute has become a unique specialized oncologic centre in the Czech Republic. It is practically the only setting in our country where it is possible to provide the cancer patients with comprehensive care at one place, where the diagnostic, treatment and nursing activities are efficiently linked with scientific research work.

Its history extends back to late 1920s, when surgeon Dr Jaroslav Bakes with his mother Lucie Bakesová, who was a social worker, founded a society called "The House of Consolation". The aim of this organization was to improve care of patients suffering with malignant tumours, and at the same time to enable a research work in this area of medicine. Thanks to the support by the first Czech president Tomáš Garrigue Masaryk and other renowned personalities everything could be realized at the beginning of 1935. During the time the name of the Institute changed, nevertheless,

its mission endowed by Dr Bakes remained unchanged: versatile care of cancer patients. At present, Masaryk Memorial Cancer Institute has the necessary hinterland for prevention, epidemiology, diagnostics, individual therapeutic modalities, nursing process utilization, physiotherapy and occupational therapy, follow-up with efficient interconnection with clinical and basic research, as well as for educational activities and health education.

Preventive oncologic programme: Prevention is the most readily available means of health protection, namely both primary, secondary and tertiary prevention, where the nurses play an important role. Good state of health means good working capacity, well-being and healthy self-confidence. Therefore ever increasing number of people realize that their health is not a matter of fact but a result of continuing personal effort. The offer of preventive programmes is of highest importance. At present, people are much better informed about cancer thanks to magazines, television, books and other resources. They start to realize that it is not the state that is accountable for their health (through the role of a physician) but they themselves through their life style and attitude to their lives.

The Czech Republic belongs among those few countries where already for several decades full-area registration of all cancers has been implemented using the so called reporting of the malignant neoplasms. The data are analyzed in the National Oncologic Register. Every year, there are tables illustrating the gross incidence, mortality, trends, age and space distribution of oncologic diseases available. This information is published by the Institute of Health Care Information and Statistics of CR. The preventive oncologic programme is based on the data of the National Oncologic Register and determines the proportion of the individual age categories of population in the total number of oncologic diseases. It determines the potential risk of the occurrence of cancers of the individual organ localizations. The survey of risks of the occurrence of the individual types of cancer in dependence on gender and age has been prepared. The Internet site dealing with cancer prevention has been put into operation.

At the Masaryk Memorial Cancer Institute all medical specializations necessary for provision of comprehensive health care of cancer patients are concentrated at one place. The Institute has 205 beds available for diagnostic and therapeutic care delivery.

Comprehensive oncologic care has been provided based on the principle of multidisciplinary approach, using a broad range of specialized services.

Nursing care has been covering a large area which has a direct influence upon the patients. The oncologic nurse has been a member of the treatment team, an equal partner having her unique mission – to care for the person as a whole, for all his/her biological, psychological and spiritual needs. The main aim is to improve the quality of nursing care so that it might respect the needs of the patients and increase their satisfaction. At all the wards, we have introduced the nursing process as a working method: from the point of view of a patient the need is understood as a demand, not as a drawback.

The implementation of the nursing process is based on active contact of the nurse with the patient. It is necessary for the patient and his/her family to trust the nurse. The nurse actively speaks in support of the patient's interests and cares for him/her with maximum regard to his/her dignity and need for privacy. The documentation system for chronological recording of the course of care delivery was introduced.

What does the nursing process offer to the patient and the nurse?

The benefits for patients/clients: continuity of care – written care plan is offered as a guide for 24 hours; coordinated care and unified attitude inspire confidence of the patient/client; prevention of errors and omissions assures satisfaction and trust in teamwork; individualized care – the care plan has been prepared based on the patient's needs, with regard to specific needs of the patient's personality as a whole; improvement of patient participation – the patient provides information about his/herself and is involved in the plan of care and discharge, which often ensures shorter hospital stay and higher patient satisfaction.

The benefits for nurses: job satisfaction – a good plan is creative, helps to use the time more efficiently and to shorten hesitation what to do next, lowers frustration and energy output; supporting knowledge development – the nurse realizes that her information resources stimulate her further desire for information and knowledge; strengthening the self-confidence – the prepared plan shows the goal, guides the nurse and thus supports the feeling of confidence and belief in the work done.

There is one fundamental prerequisite of the nursing process, namely that both the nurse and the patient contribute to the nursing process: the nurse provides specialized knowledge and abilities; the patient provides knowledge of him/herself, his/her apprehension and knowledge of his/her own problems

In the specific and organizationally demanding work of the nursing team working in shifts, this system is the basis of all planned, continuous, focused, achievable and general nursing activities. The aim of the documentation is keeping common medical and nursing records and giving clear survey of all the information about the individual patients. One of the tasks of the nursing department is to develop the system of quality management, to introduce quality monitoring at all the wards and to develop standards and standard nursing plans. This is supported by nursing informatics, which is part of health informatics. The nursing informatics integrates nursing with information science and computing technology, with the aim to increase the quality and efficiency of the nursing care. There are two reasons why understanding and development of the nursing informatics are important. The first reason is the need for a nurse to be acquainted with the latest information in the field. It is a nurse who controls the stream of information between the patient and the health care system. The nurses initiate and coordinate the communication of the multidisciplinary team of the health care providers. The other reason why the nursing informatics is so important is the demand for the nursing to be based on scientific findings and evidence (evidence based nursing) and on maximally efficient deployment of resources. The nursing care, to be efficient, needs to collect these data and store them in a standardized way, so that they might responsibly and accurately document how things are done and operate. Nursing informatics is an instrument which enables the nurses to spend more time at the patient's bed.

Introduction of the nursing process and nursing informatics in our Institute deepens the role of the oncologic nurse in nursing care delivery.

High quality nursing care of the cancer patients is the prerequisite of their satisfaction. In 2001 the Educational Centre was established which is the main provider of cancer education. Its task is to initiate and implement educational and preventive programs for members of lay and professional public. They are to provide information to cancer patients and to coordinate the activities of the relaxation centre, whose part is a creative art studio for both out-patients and hospitalized patients.

The creative art studio is an integral part of the comprehensive care of patients at the Masaryk Memorial Cancer Institute. Here, they have the possibility, within the framework of art therapy, to get acquainted with various creative techniques, among others with working with ceramic clay and wheel, plaster casts, painting on glass and silk, painting of pictures. For sick children the patients sew dolls, which serve for play therapy. We organize short courses where the patients and their family members learn new creative techniques.

Each month concerts of famous artists, theatre performances and picture exhibitions are organized for patients and their friends.

Our aim is to secure a quick access to high quality health services for the patients and to improve patient information so that they could participate more intensively in their own care both during hospital stay and out-patient therapy. The result is satisfaction not only of the patient but also of the whole professional multidisciplinary team.

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From prevention to survivorship – an overview

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A cancer diagnosis and its treatment have more than a physical impact. There are social, emotional, psychological, spiritual, and practical consequences as well. These consequences begin from the moment a person thinks they might have cancer, and continue to be experienced throughout the diagnostic interval, during treatment and follow-up care. Even if individuals do not have further evidence of disease after treatment, many struggle with long term side effects. Others must face recurrent and metastatic disease, eventually dying from their cancer. For all, there is a continuity in the lived experience with this illness; there is a sense of connectedness between all the events for the person with cancer and his or her family. What has happened early in the illness experience has an impact on what happens later, on quality of life and the person's ability to cope.

Many patients talk about their experience with the cancer care system as frustrating and chaotic. Cancer treatment is often provided in many locations and by different groups of health care professionals. Additionally, cancer patient may be treated in hospitals or outpatient settings, but they live with their cancer at home in the community. The system, in many countries, is not organized to support continuity of experience. As a result, patients feel their care is fragmented and they are often uncertain about where to turn for assistance. This presentation will highlight a conceptual framework for thinking about continuity of care and provide examples of approaches oncology nurses have used in their efforts to ensure continuity in care delivery for cancer patients and their family members.

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Integrating support services to enhance continuity of care in an Australian cancer setting

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Peter MacCallum Cancer Centre is the only stand alone cancer facility in the Southern Hemisphere. With approximately 5000 new cancer patients per annum the hospital offers a comprehensive range of medical treatments for cancer and includes the largest cancer research facility in Australia. However, while the hospital offers a range of support services, their delivery has been sporadic and lacking coordination. In 2001 we established a supportive care project with the vision of developing a collaborative, multi-disciplinary approach to support service provision that is patient and family centred and evidence based. The aims of the project are to: develop a best practice model of service provision that enhances continuity of patient care; establish an agreed staffing profile and credentialing process; and establish external links to enhance supportive care research and training. To date the project has established a supportive care needs screening tool which is currently being field tested and a range of service programs that bring together several disciplines. The project is also working to become integrated into the organisational structure to enable patient support issues to become a key aspect of the organisation's clinical governance. This paper will present progress to date on this initiative and consider the barriers and facilitators of such organisational change.