Supportive Care Roundtable

Brussels, 20 February 2018
Preface

Cancer supportive care is the prevention and management of the symptoms and side effects of cancer and its treatment across the cancer continuum from diagnosis to the end of life. It includes support for people with cancer, their families, and their caregivers. Ultimately, supportive care for people with cancer is pivotal for rehabilitation, secondary cancer prevention, survivorship and end-life care.¹

On 20 February 2018, the European Cancer Patient Coalition and the European Oncology Nursing Society co-hosted the Roundtable on Supportive Care for People with Cancer in collaboration with MEP Lieve Wierinck (ALDE, Belgium). The discussion brought together patients, nurses, policy-makers, oncologists and industry to produce concrete suggestions on improving the quality of life for people with cancer. The Roundtable succeeded in promoting the importance of supportive care for people affected by cancer and cancer nurses in Europe and raised further awareness about cancer-associated thrombosis and chemotherapy induced nausea and vomiting.

With treatment options for cancer patients becoming increasingly complex due to innovative health technology advancements, the multi-faceted care needs of people with cancer are growing. The Roundtable provided a timely forum to discuss these challenges and find tangible solutions for the stakeholder community to improve outcomes for people with cancer.

From the discussion, several challenging themes emerged as needing further attention such as nurses’ education, training and exchange of knowledge; improved communication throughout the entire cancer care pathway; the need for common guidelines; recognition of nurses’ specialisation; and further collaboration between all actors. These challenges are described within this report.

To address these issues and subsequently improve the quality of life of people with cancer, the Roundtable participants concluded with concrete solutions through European and national policy frameworks. The concrete actions in the field are summarised below.

The event was kindly supported by Helsinn and LEO Pharma A/S.

¹ http://www.mascc.org/
Call to Action

The European Cancer Patient Coalition and the European Oncology Nursing Society are calling for:

1. Policy-makers, patient groups and nursing groups to build on their collaboration and development of specific training exchange programmes in oncology and its side effects for nurses during their education.

2. Patient and nursing groups, through the support of Members of the European Parliament and Members of National Parliaments, to continue to inform their communities, with robust evidence, about the importance of supportive care, including cancer associated thrombosis and chemotherapy-induced nausea and vomiting, through advocacy toolkits, communication campaigns and other elements.

3. Patient and nursing societies to raise further awareness on cancer associated thrombosis and chemotherapy-induced nausea and vomiting and collaborate with policy-makers and other healthcare professionals to ensure further investment into primary and secondary prevention of these conditions.

4. Stakeholders to advocate for the recognition of nurses’ specialisations both at European and national levels, and for further communication skills trainings for oncology nurses.

5. The European Commission to consider cancer-associated thrombosis and chemotherapy-induced nausea and vomiting as key indicators in good cancer care and health system performance reviews.
Introduction

Cancer supportive care ensures that patient’s needs are addressed by making sure the patient’s pain and other physical symptoms are well managed. Supportive care should provide accurate information to assist people with cancer and their carers in understanding the side effects of chemotherapy and giving them the opportunity to participate in the decision making around their care.

Cancer is a disease characterised by a multitude of side effects and complex care pathways. One of the most important and potentially dangerous side-effects is the possibility of developing a blood clot. This condition is known as cancer-associated thrombosis.2

Chemotherapy induced nausea and vomiting are amongst the most distressing side effects for people with cancer. Supportive care, information and interactions with the cancer care team are crucial components of coping with these adverse effects.

Cancer is a complex disease which challenges healthcare systems to provide excellent patient care throughout the care pathway. Many of these challenges relate to the treatment and subsequent lifestyle implications for people affected by cancer and it can be overwhelming for people with cancer to learn about all of these challenges. Because of the severe lifestyle impacts of many cancer treatments, cancer nurses, who are often the healthcare professionals interacting directly with people with cancer, are providing first-hand information and psychological support. Nurses interact with people affected by cancer about supportive care, including nausea and vomiting, potential side effects of many cancer treatments and the prevention and treatment of cancer-associated thrombosis, which is an often-overlooked cause of death in people with cancer.3

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2 Cancer-Associated Thrombosis (CAT) Be clot conscious, ECPC, available at:  
3 Ibid.
When patients give consent to medical procedures or new treatments, they are informed of all the possible side effects of treatment. However, the increasing complexities of treatments mean that more information needs to be provided. Despite cancer nurses having the necessary education, they don’t always feel confident enough to educate people with cancer on these complex needs. Research indicates that only around 25% of nurses feel confident using the chemotherapy-induced nausea and vomiting (CINV) guideline, while only 35% feel confident managing chemotherapy-induced nausea compared to 59% for chemotherapy-induced vomiting. The reasons for this are twofold - the growing number of cancer treatment guidelines have created a fragmented standard of care across Europe and the continuous need for further nurses’ education. This can be addressed by developing a uniform standard of care and by increasing the specialised training that young nurses are provided during their education by providing adequate incentives. These challenges and their possible solutions were the focus of this Roundtable.

Self-management is an important part of cancer care, but appropriate information and support is needed. Therefore, a relationship between nurses and their patients which is based on strong communication is essential as they are in regular interaction. Through this relationship, nurses would be able to raise awareness about the importance of cancer-associated thrombosis, nausea and vomiting, and further empower people with cancer by providing them with necessary information.

These actions in many cases are driven by policy actions, both at European and national level. For example, in order to have a common standard for cancer nurses, their specialisation need to be recognised - a recognition which is currently lacking within the Professional Qualification Directive from 2005. Furthermore, and specifically in the field of supportive care, concrete indicators need to be established to be able to measure the level of development of supportive care in different European countries. While the implementation of health standards is the competence of Member States, the Commission’s reports in the field (i.e. State of the Health in the EU and the country specific recommendations) can provide an excellent platform to institutionalise good standards of supportive care in national health systems.

Further political support to the objectives and aims of the European Cancer Patient Coalition and the European Oncology Nursing Society in improving the outcomes for people with cancer is crucial. The continuing political support was characterised by MEP Lieve Wierinck (ALDE, Belgium) who acknowledged the continuously evolving responsibilities of cancer nurses, which go beyond their job description of healthcare professionals into survivorship and rehabilitation.

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National and European policy priorities in supportive care for people with cancer

For all people with cancer, supportive care is vital for the patients’ family, friends and for bridging gaps in knowledge between the cancer care teams. Through this Roundtable discussion, participants identified the main challenges and solutions for improving the supportive care for people with cancer.

Education

The exchange of information, knowledge and education is a crucial step in improving the preparedness of nurses and improving the quality of life of people with cancer. The European Oncology Nursing Society has many opportunities for nurses in Europe, however, experience shows that due to administrative barriers such as not being able to get time-off work, many nurses do not apply to these exchange programmes. Participants agreed that it is invaluable to increase knowledge through training sessions. Specialised training courses are a low-cost and cost-effective intervention which needs to be applied during the education period of nurses. It will provide the opportunity for young nurses to experience working in the field of cancer care, a cornerstone of their professional development. Such educational programmes can further empower nurses to provide confident and knowledgeable support to people with cancer.

Recommendation: Policy-makers, patient groups and nursing groups should encourage the development of specific training exchange programmes in oncology and its side effects, like chemotherapy induced nausea and vomiting and cancer associated thrombosis, for nurses during their education. The European Cancer Patient Coalition and the European Oncology Nursing Society should collaborate further in developing incentives for young nurses to follow these exchange programmes.

Improving communication and implementation of existing guidelines

Enhanced communication between patients and the cancer care teams, as well as within the cancer care team can greatly improve cancer outcomes. Healthcare professionals, physicians and nurses are important actors in managing the care pathway, however, communication challenges exist between these actors, which ultimately has a negative effect of patients’ well-being. Therefore, it would be important to develop dedicated checklists to assess patient symptoms such as the regularity of nausea and vomiting, and subsequently intervene appropriately.

New ways of informing nurses and the community about cancer-associated thrombosis, nausea and vomiting can also be implemented by providing people with cancer with the tools to discuss their nurses about their symptoms.

Recommendation: Encourage hospitals and National Ministries to look into the development of specific checklists (e.g. risk factors for cancer-associated thrombosis; risk factors for nausea and vomiting) which nurses can apply as soon as possible when an alert level is reached.
Patient societies, nursing societies and medical societies should also leverage national awareness days and political events to disseminate crucial information on cancer-associated thrombosis and chemotherapy induced nausea and vomiting to healthcare professionals and people with cancer.

**Indicators of good supportive care**

Cancer-associated thrombosis, nausea and vomiting are often overlooked or incorrectly communicated to people with cancer which epitomises a problem of communication in a health system. Supportive care can be an effective measurement of the wider health system performance. Possible indicators for improving supportive care could be reducing cancer-associated thrombosis and nausea and vomiting, side effects which are often observed during cancer treatment. To this end, it would be crucial to raise awareness about these potential indicators with the European Commission through their various monitoring mechanisms.

An additional key awareness indicator could be the completion of a selected education programme by a patient/nurse.

**Recommendation:** Patient and professional societies need to advocate through position papers and policy events for the establishment of cancer-associated thrombosis and chemotherapy induced nausea and vomiting as key indicators in good cancer care and health system performance reviews within European Commission’s official health evaluating mechanisms.

**The existence of variety of guidelines**

Guidelines are important tools of the patient treatment pathway. However, with too many guidelines and protocols available, there is an urgent need for an overarching consolidated approach. This approach can be politically facilitated.

**Recommendation:** In cooperation with policy-makers, nursing and patient societies need to work towards common guidelines of the patient care pathway.

In order to ensure proper implementation, the guidelines should be available in several languages and jointly promoted across Europe.

**Recognition of specialisations both at European and national level**

Nurses are the front runners in interacting with patients through their cancer care pathway. However, European legislative recognition of specialisation as an cancer nurse, is missing. The professional
qualifications Directive\(^6\) for example does not define specialist nurses which is crucial to ensure that there is a standard level of expertise across Europe to provide supportive care for people with cancer.

**Recommendation:** Policy-makers to integrate cancer nurses’ specialisation amongst professional qualification provisions.

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**Evidence based recommendations**

Policy recommendations will always need to have a strong evidence basis and to this end, the European Cancer Patient Coalition has announced that in 2019 they will produce more information on cancer-associated thrombosis, nutrition for people with cancer, nausea and vomiting.

**Recommendation:** Patient and nursing groups, through the support of Members of the European Parliament and Members of National Parliaments should continue to inform their communities, with robust evidence, about the importance of supportive care through advocacy toolkits, communication campaigns and other elements.

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**Education and awareness priorities for nurses and people with cancer**

Nurses play a pivotal role in accompanying people with cancer and their families through their cancer journey and are truly at the heart of all healthcare. Specifically, the field of cancer care is one of the most challenging disciplines for nurses. For people with cancer, cancer nurses are the ones who are there for them during their most difficult moments in life. Cancer nurses also communicate with physicians and other healthcare professions and coordinate the care of patients.

During this second part of discussions, participants addressed the problems with education and awareness priorities for nurses and people with cancer.

**Training, training, training**

More and more cancer care is delivered in out-patients settings, including home and primary care. This organisational change increases the need for further training and knowledge exchange between primary and specialist care. The representatives of the nursing community in the meeting agreed that nurses are ready for the transition to app/phone based consultations, such as the eSMART initiative.

Training should also be encouraged for people with cancer. Information on cancer-associated thrombosis, nausea and vomiting are central to patient’s understanding of his own situation. Often people with cancer lack the necessary information in order to determine if their current condition is perceived as normal or abnormal, thus not alerting the cancer care team in time. Through

\(^6\) Ibid.
patient education, people with cancer would be empowered to ask relevant questions to nurses and physicians at the right time.

**Recommendation**: Patient empowerment is key to recognising people with cancer as equal partners, working alongside researchers, policy-makers and healthcare professionals. Communication skills and trainings should be developed for people with cancer, thus empowering them to ask physicians and nurses the correct questions at the right time.

**Empowering Cancer Nurses**

Obtaining appropriate training is often not sufficient for nurses’ empowerment and confidence. Where specialist cancer nurses are part of a multi-professional team, patient report outcomes improve. Actions should include leadership development for cancer nurses to step up into shared decision-making roles within the care team.

**Recommendation**: Encourage hospitals, National Ministries, and national nursing societies to promote communication skills training to cancer nurses to navigate through challenging patient interactions. This would equip cancer nurses with adequate skills for patient communication around complex and often psychologically challenging subjects for people living with cancer, such as cancer-associated thrombosis as well as nausea and vomiting.

**Working together**

Nurses and physicians need to work together and establish a strong partnership in order to be able to provide the best preventive treatment pathway for people with cancer.

**Recommendation**: Teams of professional individuals working together to manage patient care throughout the cancer care pathway is the best way to provide treatment.

**Next steps**

Participants agreed that collaborating to implement these recommendations is the key to successfully improve patients’ quality of life. The European Cancer Patient Coalition and the European Oncology Nursing Society will look for additional endorsement of the report from Members of the European Parliament to ensure that these recommendations will result in a more comprehensive supportive care system in Europe. The European Cancer Patient Coalition and the European Oncology Nursing Society will also co-host a session on cancer-associated thrombosis in October 2018. It will take place as part of the EONS Cancer Nursing Track, attended by around 500 nurses, which runs as a satellite event alongside the European Society of Medical Oncology Annual Congress in Munich, Germany.