

level of realization. After the conversations most of the families start to plan the future, facing the upcoming death with courage from a new perspective and feels they get a better quality of life.

Conclusion: The overall results of our professional family dialogues are, that the patient's feel relieved when the unspoken has been verbalised. The patient and family now have the same recognition of the situation and therefore have better terms for quality of life.

Joint EONS/ECPC symposium

(Tue, 25 Sep, 09.15–11.15)

Meeting cancer patients' informational needs: rising to the challenge

8028

INVITED

Are patients' experiences important for nurses?

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The purpose of this abstract is to give an overview and introduction to the topic described in the title. A systematic review of literature on the types of information important to cancer patients was conducted. The review included 18 studies. A synthesis of the ranking of the importance attached to various types of information by patients in individual studies showed that information about the disease itself and information about the treatment that follows are the most important types. Information about sexual concerns and physical attractiveness was ranked least important by cancer patients overall. Also, the review indicates that highly educated patients may be similar to less educated patients in the types of information they need. As for the impact of patient situations on the need for a specific type of information, patients who prefer to be active in decision-making during illness want more information about their illness. Although some evidence existed to indicate that patients who are closer in time to their diagnosis need to understand the disease by wanting more information about their illness, the stage of cancer does not affect the type of information needed. Although it is true that not all patients wish to know the nature, cause, and treatment options for their disease, there is evidence showing that virtually all patients have a deep seated need for specific information. It has been found that having relevant information not only helps patients understand the disease but also facilitates patients' decision-making and coping. While most patients want basic information on diagnosis and treatment, not all want further information at all stages of their illness. Three overarching attitudes to their management of cancer limited patients' desire for and subsequent efforts to obtain further information: faith, hope, and charity. In descending order of use, health care professionals, medical pamphlets, and family and friends were most used information sources. Internet and support groups were least used. In descending order of helpfulness, books, health care professionals and medical pamphlets were found to be most helpful information sources. Younger patients used health care professionals and certain forms of written information sources more than older patients.

Conclusions: Cancer patients' attitudes to cancer and their strategies for coping with their illness can constrain their wish for information and their efforts to obtain it. The systematic review shows that many areas of cancer patients' information source use have been either neglected or barely analysed. An in-depth understanding of cancer patients' use of information sources and the characteristics in information sources they consider to be helpful is important for developing successful interventions to better inform patients.

8029

INVITED

Do we know what patients need?

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Abstract not received.

8030

INVITED

Access to information – the reality for European patients today

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The main patient complaint in this new Millennium of information is precisely the lack of appropriate information and communication from and with their treating physicians. The key word is appropriate and the patient lost in the face of cancer cannot rid himself of anxiety and uncertainty in front of his physician who always seems to lack time. Information and adequate education have general and specific goals in all aspects of our civil society but are absolutely vital in guiding cancer patients

through the scientific labyrinth of modern up-to-date medical diagnoses and treatment. It is virtually impossible to elucidate the complexity of optimal medical treatment in one sweeping move. This information has to come in steps to avoid overwhelming information from the internet, incomplete information from the physician and contradictory information from friends and media. It is even more difficult to exchange information on a similar wavelength in dealing with the fear and panic as part of holistic patient care. The recognized need for a multiprofessional cancer treatment enhances the problem and existing barriers should be eliminated for a timely and empathic patient journey through the emotional stages of diagnosis and decision making in cancer treatment. This process demands more than patient information and requires the adaptation and education of the care team trained to treat cancer cases with limited time to understand the individual person behind the case. This lack of access to adequate information and communication exists for all consumers of our health care system in variable degrees. Serious progress has been made in pediatric and female health care by dedicated organisations including EONS and Europa Donna. Similar efforts are provided for geriatric and male health care where patient organisations such as Europa Uomo in direct collaboration with the professional organisations work towards a well informed patient, engaged in his own and others welfare, leading to better management decisions and optimal outcomes.

8031

INVITED

Meeting patients' informational needs: a practical example

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Introduction: After diagnosis, many cancer patients will receive an abundance of information about their disease, possible treatments and its side effects. This often occurs during a relatively short period of time during which patients' are struggling to come to terms with the cancer diagnosis. Under these circumstances it is difficult for many patients to retain and understand the information given. Furthermore patients have varying information needs, while some actively avoid detailed information; others will go to great lengths to educate themselves in every aspect of their diagnosis and treatment. A CD-Rom concerning Stem Cell Transplantation was developed as it has the potential to provide comprehensive information that can be accessed according to the patient's individual requirements. The CD-Rom was produced primarily for patients, their family and relatives. However, it can also be used for training purposes by both clinical and education staff.

Subject: The CD-Rom comprises audio, video, animations, pictures and the possibility of printing relevant sections. It consists of two separate components: Part one describes detailed information regarding the whole treatment course from diagnosis through to post discharge care. The second part consists of interviews and the case history of eight different former patients lasting twenty minutes each.

The information concerning treatment of part one is divided into six modules: 1. diagnosis, 2. the hospital, 3. Stem Cell Transplantation including the preparation like chemotherapy and radiotherapy, 4. side effects and their management, 5. neutropenia and 6. discharge and home situation.

The information is sequenced in order of the patients' treatment course and can be used in that order, although it is also possible to go directly to modules which are relevant to particular patients and their particular needs. The patient case history can be used in combination with the relevant information or both sections used independently. The system used to compose the CD-Rom makes it relatively simple to utilise the information or make it suitable for other institutions or even other treatments. Although the CD-Rom is in Dutch the principles are transferable and could easily be used in other languages and even other treatments.

Results: Distribution of the CD-Rom started in the spring of 2006. The patient is given the CD-Rom to take home following consultation with the doctor or transplant coordinator. This enables them to access the information in their own environment with or without family, at a time suitable to them and with the option to repeat or skip sections as they like. These properties along with the audiovisual properties of the CD-Rom provide a method of information which is easily retained. Although a survey is running, the first responses have been very positive. Finally patients felt that information given at home is more likely to be remembered.

The interactive CD-Rom looks a promising supplement next to the existing methods of patient education.