I am a television presenter who survived advanced colorectal cancer and now chair the Board of the ECPC. When I was diagnosed, 14 years ago, doctors in the UK were not trained in communication skills. I had no specialist nurse to offer support. I couldn't find any information about colorectal cancer. Looking back, it seems like the dark ages.

Over the years I have heard from and talked to thousands of cancer patients about their experiences of the cancer journey. To summarise – the communication needs of cancer patients include:

- the right information at the right time
- the need to see the person not the disease
- treating patients with dignity, as partners in their care
- helping with informed choices/treatment plans/even reassurance about best practice
- the importance of medical support after diagnosis, especially specialist nurses
- enabling the sharing of experiences with appropriate trained patients who have already survived/travelled the journey
- the opportunity to join support groups

The right information at the right time includes:

- availability of simple written detail about what might happen at each stage of the journey
- access to medical professionals
- knowledge of the importance of health literacy – language, readability, ethnicity, spoken alternatives to written material
- informed choice increasingly involving questions like "how good is my hospital? How can I get a second opinion without compromising care?"
- other sources of help/support including patient organisations, the internet, financial support

Ways of finding out what cancer patients need from their hospitals/institutions:

- "patient feedback parties", pioneered at a fifth of colorectal cancer units in the UK
- cultivating UIPs (uniquely informed patients) who have a wider perspective than their own experience
- the TV "Point of View" trick

The motto of the European Cancer Patient Coalition is – Nothing About Us, Without Us! To get the communication needs of patients right – patients need to be involved.

1568 Abstract not received

1569 INVITED

Educating oncology professionals to effective and culturally sensitive communication with their patients

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Communication is the basis of any human relationship, including the one between the patient and the health care provider. In oncology, communication is especially difficult, due to the complexity of the illness and its treatments and to the intense, and often extreme, physical and psychological suffering that is associated with many cancers. Moreover, cultural differences between the patient and the health care provider are often a source of misunderstandings and disagreements at the bedside. Thus, effective communication in the clinics needs to be culturally sensitive. Each person's identity is shaped by her culture. Culture provides each person with a reference framework to interpret the world and to relate to both external and internal events, including illness.

One of the key elements of culturally competent cancer care is understanding and respecting cultural differences in truth telling about diagnosis, prognosis, treatment decisions and end-of-life matters [1]. Communication in clinical medicine goes beyond simple unilateral information and it rather involves a bilateral constant honest exchange between the partners. It is well known that insufficient and/or improper information can hinder the possibility of effective communication between the patient and the health care provider from the beginning. However, there are major differences in patients' and health care providers' truth telling preferences, attitudes and practices [2]. Most of these differences in truth telling arise from the delicate interplay between the principles of autonomy and beneficence in medicine, under the influence of cultural variables [3]. In healthcare, patient autonomy is the leading principle of Anglo-American bioethics, where truth telling is considered a necessary requirement for self-determination. However, many cultures are centered around family and community values rather than on individual self governance, and in clinical medicine partial or non-disclosure of the truth to cancer patients are often favored. While there is a trend toward increasing information about cancer diagnosis throughout the world, truth telling about prognosis and end-of-life issues remains a matter of intense debate [4]. As a result of the growing number of multi-cultural medical encounters in contemporary societies, the ability to successfully negotiate cross-cultural issues has a fundamental role in the practice of oncology [1,5]. Cultural sensitivity and cultural competence [6,7] are now an essential requirement for all oncology professionals. Cultural competence entails the acquisition of specific skills and attitudes, which will be reviewed and discussed.

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1570 INVITED

Information technology tools in support of patient communication

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Background: Internet communication technology (ICT) gives access to a massive body of information about cancer treatment and has been increasingly used through the last decade. In North America 64% of the population now seek health information on-line, while only 23% of the population in Europe (range 41−12%) use the internet for health information.

ICT is increasingly used by cancer patients for information and support. A number of studies on the internet use of people with cancer find, that increased well-being is related to using internet based support groups and internet health information.

Discussion: Creating environments for information and communication, making the most and the best of ICT in cancer care face several challenges: access to ICT is unequally distributed and the quality of health information on the internet is uneven.

There is growing evidence that cancer patients are empowered by use of the internet to take an active role in their treatment decision-making process. Research also finds that the internet continues to play an important role for cancer survivors after finishing medical treatment.

Oncology professionals can use the internet as a patient educational tool giving the patient time to absorb sometimes complicated information. The internet has also been used successfully to monitor symptoms and side-effects of cancer treatment. Through the internet new possibilities emerge for providing different cancer interventions to patients, without regard to time or place. It has furthermore been found that ICT in cancer care has a potential to reach underserved populations, but access to ICT is still a problem in this population.

However, the use of ICT for information and support does not necessarily result in better patient-provider communication. Patients often convey that while being well informed, enhanced empowerment and control on a personal level, the attempt to engage actively in the decision-making process is met with hostility and irritation by health professionals. Health care providers on the other hand describe, that they experience patient to form unrealistic expectations and unnecessary anxiety based on information from the internet, and they feel unable to answer to such demands.

Educating patients and providers to utilise the benefits of ICT is important to enable the best use of the internet in cancer care.

Conclusion: Internet communication technology holds a large potential to empower cancer patients and develop new initiatives in cancer care.