

Parallel Sessions B

B4 - From Consumer Health Information to Evidence Based Health Care

Friday, September 20, Room E, 11.00

## **An Italian Oncologic Integrated Databank for Patients: Just to Begin a Path**

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Italy can not be considered to be a country with a great tradition of production of health literature for common people and patients. The main reason for the poor production of consumer health information might be a typically Italian idea of patients as passive subjects who have mainly to follow doctor's indications. Informed consent, compliance to treatment, information for a better participation, are concepts not so consolidated in our culture. In the eighties, the computer revolution first and the Internet revolution then, caused also in Italy a great cultural change. Nowadays, in the Web time, things are rapidly evolving: many subjects are producing information and many are using it. But, the lack of tradition in this field is not without consequences. Quantity, in fact, is not a synonym of quality and both quantity and quality without infrastructure, know-how, and organisation, are not synonym of good information. This is particularly true in the field of information for cancer patients.

In our library – a specialised library of a National Cancer Institute located in the North East of Italy, created to mainly support information needs of the staff and specialists - we have never refused to give information about cancer to patients, relatives and friends who wanted to be more informed about their illness. Performing such task, we met two serious problems: first, insufficient availability of information addressed to common people and patients in Italian language; second, lack of collection of such materials. So we started a project called "Biblioteca per i pazienti", by creating a new section in our library where an expert person was appointed to give information on the basis of a good amount of materials: grey literature above all, but also other kind of materials in all formats and supports. We took inspiration from many international experiences - PDQ-NCI, CAPIHS-Consumer Patients Health Information Services, a section of Medical Library Association, USA, Medline Plus; BACUP-UK... just to cite some of the most important – but we add our "Mediterranean style" of communication.

We early experimented that the main problem was not related to the scarcity of materials for patients - i.e. leaflets, guides, booklets, cassettes and CD-ROM, websites - but to the lack of a catalogue. Before the Internet era, it was really difficult to know the availability of specific documents for common people and patients; now, the problem is the evaluation of the growing amount of information and this problem is particularly significant because our users are cancer patients or patients with a no good prognosis. People coming to our library often need a help to wriggle out of the huge quantity of information found in Internet.

So, we decided to create an Italian Oncologic Data Bank of Literature for patients and common people in order to supply cancer patients, their relatives and friends with an easy tool to meet their information needs. Our archive is now consisting of about 500 bibliographic records of grey and white literature for patients (Medical Subject Headings translated in Italian have also been added), about 50 full-text documents and a directory of about 200 associations in the field of cancer care in Italy. We are now enriching this core archive and validating it according to the international standards of qualitative evaluation of biomedical information with the contribution of an Expert of Information Evaluation ("enriched" HON code). An unique interface allows users – both end users and librarians or caregivers - to search any of materials and information and also to borrow them. A CD ROM, a Website and a printed catalogue are in progress.

The Oncology Group of BDS, the new Italian Association of Health Librarians and Documentalists, born in 2002 - has the idea to co-operate, in order to transform this core papery and electronic archive in a real Italian Integrated Oncologic Data Bank of Literature for common people.

Last but not not least, our project has just got a special award in Italy "Five Stars Prize", as better project in the field of Health Promoting Hospitals.

So "Acting locally, thinking globally" well represents our goal: starting from a local situation, we are now cataloguing and making available more and more information and based information services for patients in order to give patients, their relatives, friends and common people a more qualified and friendly-user tool of information, in order to empower them.