



Centro di Riferimento Oncologico
Aviano, Irccs - Istituto Nazionale Tumori
Italy

8th EAHIL CONFERENCE
16-21 Sept 2002, Koeln
“Thinking Globally, Acting Locally”

Topic: Consumer health information and libraries

“Living with cancer”:
An Italian Oncologic Data Bank of Literature for
patients and common people: just to begin.

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1. Introduction
 2. Our project "Biblioteca per i Pazienti"
 3. The Oncologic Data Bank of Materials for patients and common people
 - a. The beginning
 - b. The evolution
 - c. The future: the Integrated Italian Oncologic Data Bank of Materials for patients ...
- Conclusions
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1. INTRODUCTION

- In Italy, there is not a great tradition of health literature for common people and patients

The main reason :

- a typically Italian idea of patients as passive subjects, *not as a real co-protagonist in the "master relationship" Doctor-Patient*



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- *"Informed consent"*
- *"active compliance to treatment"*
- *"information for a better collaboration and*
- *"participation to the care"*

are concepts not so consolidated in our culture

But slowly something started to change...



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In the eighties, also in Italy,

a great cultural change mainly due to:

- A. Computer revolution
- B. Internet revolution

Effects..

Nowadays, in the Web time,

- a huge production of information for all kind of users
- an increasing number of users



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But...

- Quantity is never a synonym of Quality
and
- both quantity and quality without know-how,
validation, management, organisation...
are not a synonym of good information
(BMJ mar 16, 2002)



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**This is particularly true
in the field of information
for cancer patients**



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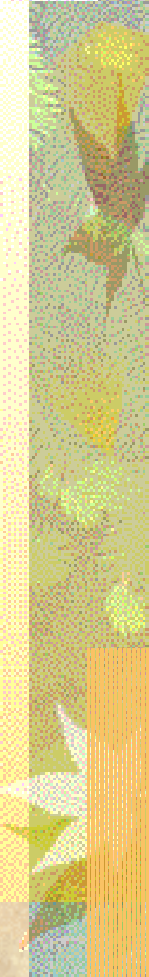
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2. OUR PROJECT "BIBLIOTECA per i PAZIENTI"

The context:

- Our Library is a specialized Library of a National Cancer Institute located in Aviano, North East of Italy
- The CRO Scientific Library is a Unit of the Scientific Direction of the Institute





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The first mission of our Library is:

- to support information needs of every category of the staff according to the evergreen Ranganathan's indications, in a pro-active way:

Books are for use

Every reader his book

Every book his reader

Save the time of the reader

The library is a growing organism



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2. OUR PROJECT "BIBLIOTECA per i PAZIENTI"

But since the Library opening (1984),
our vision was to:

**Never refuse
information about cancer
to patients, relatives and friends
who wanted to be more informed
about their illness**



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2. OUR PROJECT "BIBLIOTECA per i PAZIENTI"

Two problems on the basis:

- a. insufficient availability of information for laymen and patients in Italian language
- b. lack of collection of such materials

It was necessary to make a specific project of Information Service for patient

It was necessary to make a specific project of Information Service for patients



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2. OUR PROJECT "BIBLIOTECA per i PAZIENTI"

- **In 1997-1998 we planned a project called "Biblioteca per i pazienti", i.e. "Library for patients"**
- **Before, we realized a survey among hospital patients and outpatients about the need of supplementary information about cancer: 63% stated to need more information in hospital...**



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2. OUR PROJECT "BIBLIOTECA per i PAZIENTI"

- "The Library for patients" but also
"The Patients' Library"
is a creation of an Interdisciplinary Team of librarians, psychologists, doctors, nurses, experts in informatics, press officers, patients...
- The project was made by a restricted "Lib/Psy" Group
- approved by the Direction of our Institute and by the National Health Authority, too



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2. OUR PROJECT "BIBLIOTECA per i PAZIENTI"

- It's co-ordinated and organised by the Librarian and a Psychologist, managed by an Expert of information and communication, supported by the Library Staff with the collaboration of a Group of Experts, placed in the Scientific Library



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2. OUR PROJECT "BIBLIOTECA per i PAZIENTI"

- **The project had a good success: more than 1.000 patients and relatives, and much more topic requests...**
- **It rapidly became a pilot project in the field of information for patients in Italy...**



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The "Library for patients": some key words

- it's a special section of the CRO Scientific Library
- there is an expert person appointed to give
- appropriate materials in answer to
- specific requests of patients, relatives and friends.



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Some other features:

- It aims to collect appropriate materials and to create an Italian data bank of such materials for patients as basis of the service
- A "Mediterranean style" of communication:
 1. Attention to the person
 2. Information is for patients, for helping them to better cope with cancer not simply to increase their knowledge...



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Some inspiring international experiences:

- **CAPIHS**- Consumer Patients Health Information Services, a section of Medical Library Association, USA
- **BACUP**- British Association of Cancer United Patients, UK
- **Medline Plus** and
- **PDQ** - NCI, just to cite most important, but our project has some peculiarities:
- information about cancer plus diversion books
- intermediation, communication style etc...



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3. **A first provisional conclusion:**
- The main problem in Italy in the field of information for patients about cancer **is not the scarcity but**
 - the leak of materials
 - the proliferation of every kind of information in the Web time
 - the lack of validation, coordination, cooperation...



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3. OUR ITALIAN ONCOLOGIC DATA BANK

- These are the motivations for creating an Italian Oncologic Data Bank of Literature for patients and common people
Its target
- To supply cancer patients, their relatives and friends with an easy tool to meet their information needs



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3. OUR ITALIAN ONCOLOGIC DATA BANK:

Now

- about 400 bibliographic records of "grey and white literature" for patients, mainly in Italian language, coming from various sources: associations, hospitals, no-profit
- popular works - like articles, chapter books, magazines etc... but also
- some scientific issues
- about 50 full-text documents



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3. OUR ITALIAN ONCOLOGIC DATA BANK:

Now...

We are enriching this core archive with:

- popular works about cancer available in different formats: books, magazines, chapter books, articles, leaflets, CD, cassettes, web sites, etc...



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3. OUR ITALIAN ONCOLOGIC DATA BANK

Now...

- We refer to a Group of Experts - doctors, nurses, psychologists - for any problems related to materials ("hot topics") or to particular patients' requests
- All these documents are validated according to the international standards of qualitative evaluation of biomedical information...



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3. OUR ITALIAN ONCOLOGIC DATA BANK

We are working to...

- An unique interface to allow users - both end users and librarians or helpers -
- to easily search the various information resources and also
- to get or borrow them

A Web site, a CD ROM and a printed catalogue are in progress (by November 2002)



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3. OUR ITALIAN ONCOLOGIC DATA BANK

We are working to...

- A re-evaluation of Web sites, documents and electronic resources according to a specific evaluation scheme ("enriched HON code", Gardois)
- a promotion of the original writing (by specialists) of papers for Italian patients about cancer topics still not covered



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3. OUR ITALIAN ONCOLOGIC DATA BANK

We are working to...

- a survey of the Italian cancer associations, no-profit organizations etc...both producers of documents and not
in order to implement
- a systematic description of these important resources for patients living with cancer



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4. The Italian Integrated Oncologic Data Bank of materials for patients

In the next future:

- The Oncology Group of BDS - the new Italian Association of Health Librarians and Documentalists, born in 2002- had the idea to co-operate for transforming this core papery and electronic archive in a real Italian Integrated Oncologic Data Bank



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In the next future:

- A specific project was made: "AZALEA"
- It could be successful because of :
 - the sharing of the same cataloguing and Web integrated software used for the core archive
 - an already "tested" co-operation among biomedical librarians (BDS)



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In the next future:

Some features of the Italian Integrated Oncologic Data Bank... "Azalea"

- Availability of documents
- Interchange modalities with rules
- A larger description of authors/editors
- Abstracts, more full-text documents ...
- MESH subjects translated in Italian added to English ones...



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5. CONCLUSIONS

- Our "master project" of Library for Patients" has just won a special award in Italy at ExpoSanita, Bologna May 2002, "Five Stars Prize", as best project in the field of Health Promoting Hospitals



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- "Five Stars Prize" is a special competition organised by Azienda-USL Bologna Nord, aiming to sponsor the best planned and realised projects in the field of hospital comfort, information, communication, customer satisfaction, perceived quality.



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**The "Five Stars" grant
will allow us to realize
the first release of the
Italian Oncologic Data Bank
of information resources for patients and common people**



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ACKNOWLEDGEMENTS:

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- all the professional and non-professional people who collaborated with us
- A single thank to AIMaC, the equivalent in Italy of BACUP, extended to all the Italian Associations for helping people with cancer
- A special thank to "Cittadinanzattiva", the Italian no-profit Organisation for Right's Patients, who first believed in our project.



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THANK YOU for your attention

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