

Working together in a Patient Education Group: a possible new role for a biomedical librarian

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We are speaking about:

The importance of IMPROVING

- INFORMATION
- COMMUNICATION
- CARE

in a HEALTHCARE ORGANIZATION THROUGH the INVOLVEMENT of the PATIENTS and the ACTIVE CONTRIBUTION of the LIBRARIAN

In fact:

Consumer health information services,
supported within libraries in the Cancer
Institute, serve an important function:

**as CATALYSTS of the
PATIENT EDUCATION PROCESS**

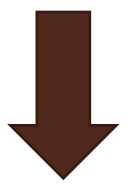


Objective:

Exploring the positive and active role of the librarian within the PATIENT EDUCATION GROUP (PEG), as a resource that helps patients improve communication with their doctor and get them to take a more active role in the management of their illness

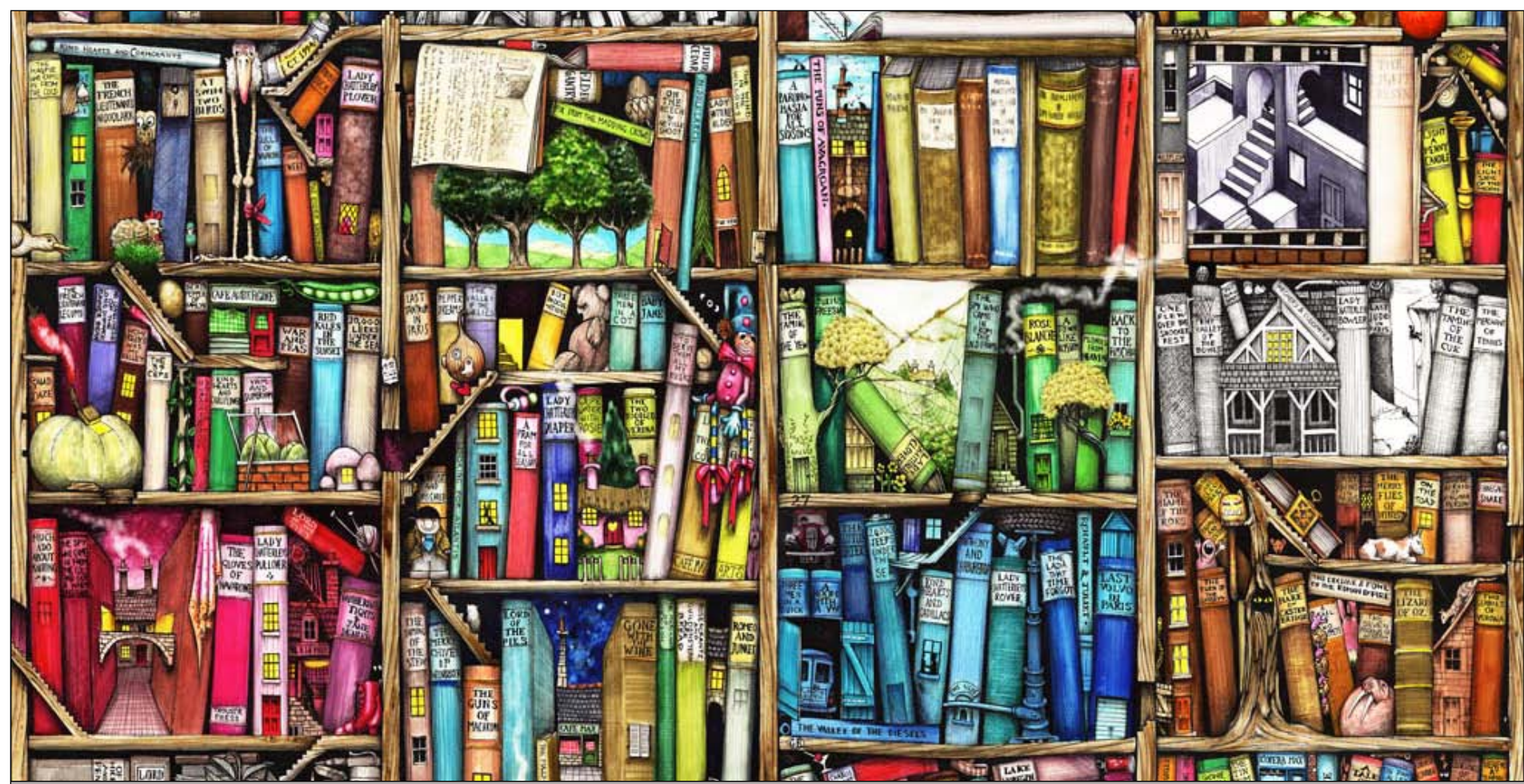
**Comprehensive
Cancer Centres
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the two aspects of
health staff
education
and
patient education**

- Cancer Comprehensive Centres (in Italian IRCCS), like our Institute, are both Hospitals and Research Centres;
- There is a tradition in the health care organizations of continuing education for the health staff (in Italy this is a must) and usually the librarian is involved in this process.



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- Patient education has been recognized as a fundamental component of health care, especially crucial to ensuring that patients are knowledgeable about their treatment options, the management of their healthcare needs and the effective use of medication;
- But there is no tradition in:
 - involvement of the patients in the patient education process
 - involvement of the librarian in the patient education process



Two important concepts to deal with the issue:

Patient Library

At the Centro di Riferimento Oncologico (CRO), one of the eight Comprehensive Cancer Centres in Italy, a pilot experience in the patient information field - the “Patients’ Library” experience- has been developed dating back to 1998 – first in Italy

The activity of the Patient Library are about:

- Oncological point of reception and information
- “Bibliobus”, that means library and leisure activities



Patient Education

The teaching or training of patients
concerning their own health needs

(MeSH)

an important role is to guide the patient in his/her care process

Patient education... a complex definition



- MeSH definition concerning learning and training
- In the American Academy of Family Practitioners' (AAFP), patient education is defined as “ the process of influencing patient behaviour and producing changes in knowledge, attitudes and skills necessary to maintain or improve health”
- The information component is crucial as well as the involvement of patients in the healthcare organizations

our idea is based on...

EMPOWERMENT



on the involvement of the patient in many activities related to a patient education program such as: writing booklets and guides, writing scientific articles, evaluating the readability and comprehension and utility of patient education materials, organizing the diffusion of the informational material, reading clubs, narrative-based medicine meetings, empowering their advocacy for obtaining some changes in the organizations programmes (day hospital organization, hospital food, patients rights etc...)

The aim is:

To make patient real actor of his care process

We adopt the expression of Jan Geissler
(former president of European Cancer
Patient Coalition – ECPC):

“Nothing about patients,
without patients!”

Patient education group

An example:

(from Gaynor et al. “Putting the pieces in place: the patient education puzzle” *J Nurs Care Qual* 1998)

“the members of the Patient Family Educational Advisory Committee – a multidisciplinary task force - included clinical nutrition, pharmacy, rehabilitation services, psychiatry, cardiac and vascular services, and HIV clinic, along with various nursing areas, where their missions include developing and promoting strategies for health care professional”

Where
is
the
Librarian?



An effective patient education group (PEG) must be a coordinated effort by the practitioners of all disciplines involved in the continuum of care

We believe that:

the development and success of a

Comprehensive cancer-specific

patient information binder was only

possible with the contribution of an interdisciplinary team of

health care professionals working toward the same goal—

providing accurate and appropriate information to cancer

patients and their families



CRO model

Created by the Scientific Director of our Institute, the PEG includes all the directors of the clinic and research units that interact with the patients.

The group is multidisciplinary and it is made of

- doctors,
- nurses,
- secretaries,
- pharmacists,
- librarians and...

the “special core” of the group

it was decided to include two patients’ representatives and two representatives of the volunteering organizations, as a value added to the group: these figures constitute, the “core” of the group, and the key instrument to change the practice of doing things for the patients to one of doing things **with the patients**.



Health librarians, because of their knowledge and training in the identification, selection, organization and dissemination of evidence-based information, play an important role in both consumer health information services and patient education. The increasing emphasis on patient-centred care in the United States, and the accompanying need for better-informed patients, provides a great opportunity to integrate librarians more fully into the health care team.

the management of PEG was committed to the librarian

WHY?

The decision of giving this role to the librarian was due to his/her “neutral”, “contour” role with regard to all the other involved skills and figures.

At the same time, he or she is the figure that can most easily coordinate and catalyze their efforts.

Relevant points for library related to patient education (awards' "official")

Our requirements:

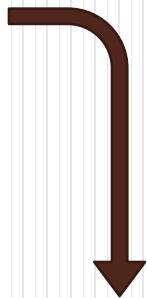
- “Five Stars Prize” (2002) to the Patient Library in a national competition for perceived Quality’s projects;
- Recognition of regional interest to the library “because it also used by patients”(2009);
- Starting from 2009 our Institute undertook an accreditation and certification path based on the “Accreditation Canada” program, methodology and standards. In the first report the library was perceived as a “reference point” in the patient interviews;
- The CRO Information Point – section of the Patient Library - is part of the Italian Information System to cancer patients.

Relevant points for library related to patient education (daily activity)

- Reference activity: relationship with the patient to meet his demands;
- Publishing: information books and books of testimonies, reflections of patients;
- Patients suggestions 'list for improving some facilities of the hospital (thanks to the particular librarian-patient relationship: the librarian is not directly involved in the medical care and so the patients feel free to express their concerns in a neutral setting);

Relevants point for library related to patient education (daily activity)

- The librarian is not a psychologist but he can use his communication competence and knowledge for accepting these concerns and promoting and support the patients' rights and interests.
- Analysis of the material best suited to meet the needs of the user



guide the patient in his/her choice of education

~ in particular in the web era ~

the information found on the web need to be filtered and may include voluminous misinformation or nonrelevant information.

One of the reference databases is Medlineplus.gov



Italy currently lacks a database providing quality clinic information for patients – realizing it is one of the Library's goals



CIGNOWEB



How does a patient librarian work ?

Patient Library's code of ethics

We obtained to translate and adapt the
Ethical Considerations ,
part of the Consumer Health Manual of the
National Network of Libraries of Medicine
<http://nnlm.gov/outreach/consumer>.

Consider the following :

guidelines for the consumer health reference interview - adapted
from Healthnet: Connecticut Consumer Health Information
Network

- Provide a welcoming, safe environment
- Be aware of the person asking the question
- Get as much information as possible
- Verify medical terminology in a medical dictionary or encyclopedia.
- Be aware of the limitations of medical information
- Provide the most complete information to answer the information request.
- Do not interpret medical information
- Provide referrals

What is the mission of the PEG?

The mission of this Group is to improve information and communication between doctors and patients, between the health staff workers, and between the CRO and the general public, all with the involvement of patients.

Learning to work together successfully is part of the mission.



Obectives for this first year:

- Research 

The research is about “Immigrants and health related issues” in our area. The investigation project on the presence of immigrants and on the ease of their access to our Institute is currently in the administration phase. The questionnaire – a perception-questionnaire - was distributed to every Institute staff member who interacts with the patients, as well as to cultural intermediators working in the Institute’s area.

- Education

- Information & communication



Obectives for this first year:

- Research

Workshops and focus groups with the patients are organized both to discuss topics, to present the activities' results and establish further activities

Topics of the meetings are based on the needs and demands of patient representatives and voluntary

- Education



- Information & communication



Obectives for this first year:

- Research
- Education
- Information & communication



Writing patient-oriented information material with the contribution both of the healthcare workers and of patients themselves is a further issue of the Patient Education Group. This series of publications is a tradition for the Institute, since it has always made use of editorial initiatives for clinic and other purposes.



The contribution of the librarian, as an information specialist, is critical.



production of quality information material for patients

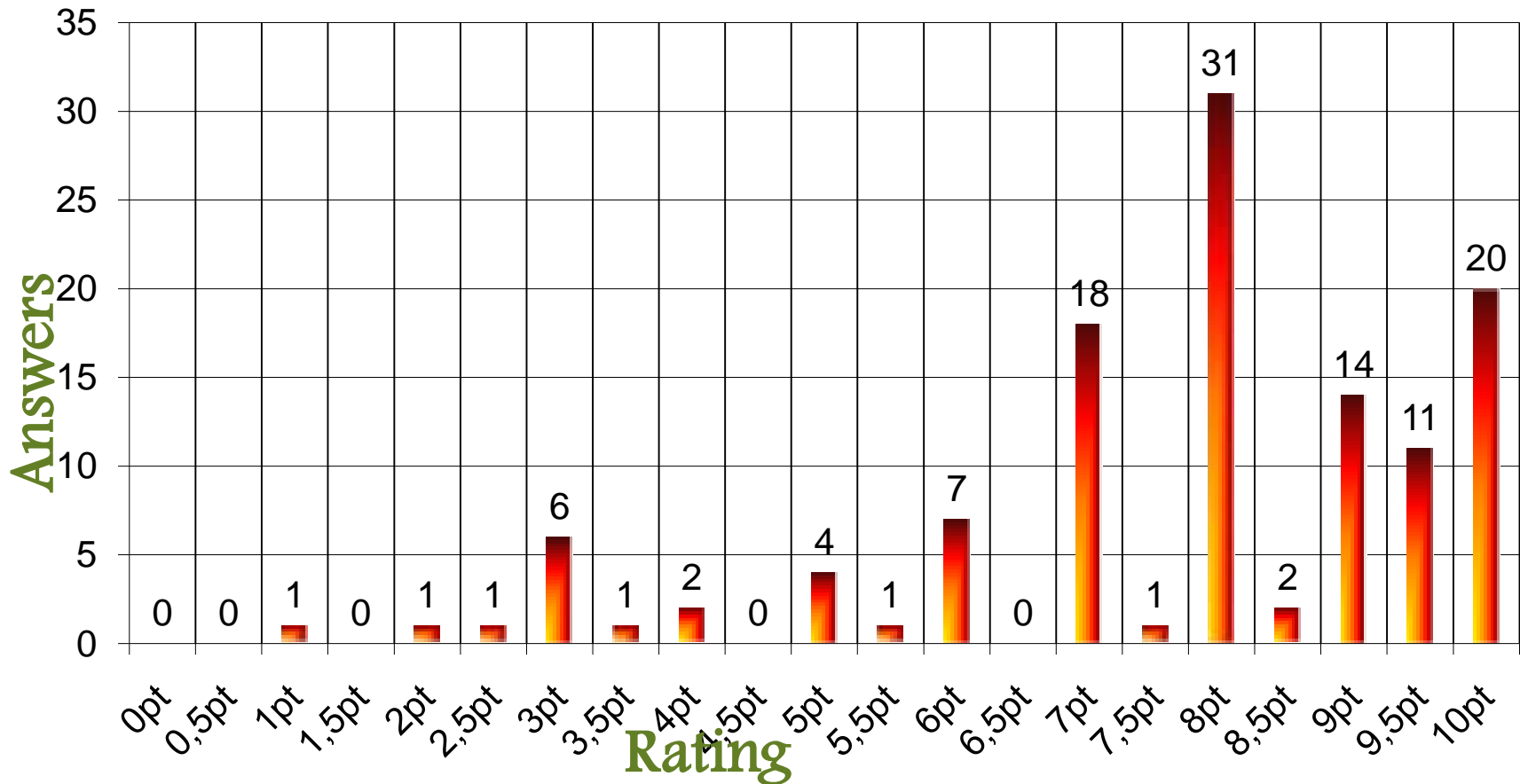
We have realized, to date, six “CROinforma” guides: these are “popular science” booklets, targeted both for patients (“from biology to medicine”, “how to better know and use antibiotics”, “oral mucositis”, “after cancer”) and for general practitioners (“hereditary colorectal cancer register”, “inherited predisposition to breast and ovarian cancer”). The uniqueness of the project and the stylistic coherence of the “CROinforma” guides, though, made for a useful product that proved to cater to the patients’ informational needs.



ANALISIS:

An evaluation questionnaire on the “hereditary colorectal cancer register” guide was sent to 500 general practitioners (GP) of the Friuli Venezia Giulia region. We received feedback from 120 GP’s

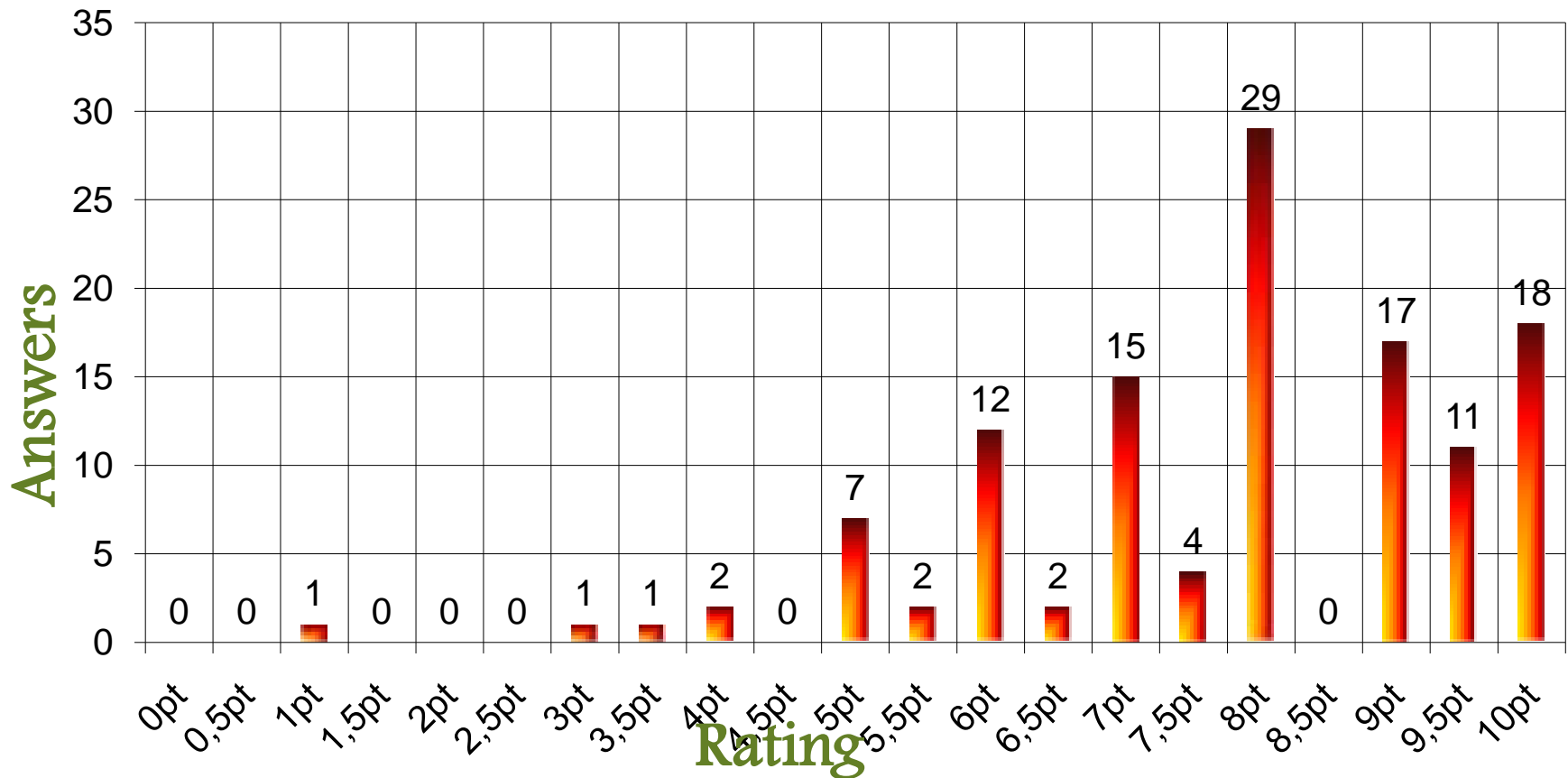
informational usefulness



ANALYSIS:

An evaluation questionnaire on the “hereditary colorectal cancer register” guide was sent to 500 general practitioners (GP) of the Friuli Venezia Giulia region. We received feedback from 120 GP’s

typographic agreeability



We are working for a similar survey conducted on patients' evaluations, to verify their appreciation

In fact

When patients have the knowledge they need, they are in control, which reduces their fears, anxieties, and distress. Family and friends reported an improvement in their ability to communicate with, and understand the needs of the person close

to them who had been diagnosed with cancer

Roberts S et al. "The Living with Cancer Education Programme. II. Evaluation of an Australian education and support programme for cancer patients and their family and friends" *Eur J Cancer Care* 2002



Raccomandation for better Patient Education action

To reduce the barriers on retrieving quality information material, and understanding it -a difficulty often due to emotional impact and having to connect with a very different reality, it is recommended to use a specific and individual approach to patient education





New figure?

PATIENT EDUCATOR

- Patient educators must initially assess the patients' needs, willingness or ability to learn, and their preferred learning styles
- may include interviews with the patient or family members
- communications with members of the medical team
- observations of patients
- administration of questionnaires

Also, the patient educator can implement patient education by means of verbal communication supplemented by written materials. Finally the patient educator must evaluate whether the patient has met the educational objectives



A final question....

Is it possible to intend the patient educator as a patient librarian?

Are librarians able to provide their users with informative recommendations regarding the selection of search engines, effective search strategies and assessment of web resources for patients?

Can they play an active role as Patient Educators, specifically trainers of Patient education processes?

CONCLUSIONS:

- The patient librarian supports empowering the patient to be a partner in his or her care;
- Patient Education is a complex process involving many stakeholders in the healthcare organizations;
- Cancer Institutes with translational vocation represent a particularly fit setting because of the active role of the cancer patients;
- Librarians can play an active role in this process if they believe that being involved in this field can be part of their profession, interests, and skills.



Thanks for the attention!

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