Helping patients get up from their knees...

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The focus

- The focus of my speech is the concept of Empowerment in practice from a biomedical & health consumers librarian’ point of view.

- There is a big debate in the scientific literature about the concept of Empowerment and its theoretical and practical implications when applied to healthcare.

- This debate usually does not include the libraries/librarians as potential co-actors...
Health librarians because of their knowledge of and skills in...

The librarian’s role in the provision of consumer health information and patient education

Policy Statement by the Medical Library Association and the Consumer and Patient Health Information Section (CAPHIS/MLA)

Health librarians, because of their knowledge of and skills in the identification, selection, organization, and dissemination of information, play an important role in both consumer health information services and patient education. The role of the librarian differs depending on the mission and policies of the organization. Librarians’ activities in this area are oriented towards the goals of producing a healthy society and assisting the individual in making informed health decisions. This policy statement, approved by the Board of Directors of the Medical Library Association, was developed by the Consumer and Patient Health Information Section. It covers MLA policy, defines consumer health information and patient education, and identifies potential roles for librarians in these two areas.

- Building an authoritative collection of CHI and patient education materials in print and electronic form that meets the needs of the institution or community being served.
- Developing subject file collections on current topics of interest to consumers, etc.
- Maintaining a current collection of CHI and patient education materials which are routinely reevaluated and revised.

Knowledge and resource sharing

- Networking with other individuals, organizations, and agencies to facilitate resource-sharing of CHI and patient education materials.
- Consulting on the identification, selection, and organization of patient education materials in health care settings, e.g. hospital nursing units, ambulatory clinics, etc.
- Serving on institutional committees that address topics such as patient education, public health, community health education, quality assurance, medical subject access, and interlibrary loan.

Bull Med Libr Assoc 84(2) April 1996
Our aims

- The first goal is to expose the knowledge and skills that a librarian can use in order to play an active role in the patient education & empowerment process.
- The second one is to demonstrate the methodology and some preliminary results of a practical experience of Patient Education & Empowerment, ie ...
- what happens when librarians are involved...
What is Empowerment

- Power (psychology) is the preferred term for Empowerment in the Mesh/PuMed database

- Patient empowerment = a process that helps patients gain control over their lives, increasing their capacity to act on issues that they themselves define as important;

- A process through which patients *individually and collectively* are able to...

(Adapted from JA-PaSQ, 2012 by Robert Johnstone, EPF/IAPO)
Robert Johnstone (of the International Association of Patients Organisations) says that “doctors should get down from their pedestals, but patients must get up from their knees.” Yet he adds: “empowerment is not about trying to wrest power from the doctors, it is essentially helping people lead more proactive and fulfilling lives.....”
... (BMJ 2013;346:f2614)

Let the patient revolution begin

Patients can improve healthcare: it’s time to take partnership seriously

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A hundred years ago George Bernard Shaw lambasted the medical profession as a conspiracy against the laity. Today, disease and doctor centric health systems that are costly, wasteful, fragmented, and too often uncaring are provoking similar ire.

Despite the best intentions and undoubted skill of many who work within healthcare, access to care, and its quality, vary markedly, and most people in rich countries access a confusing smorgasbord of tests and treatments whose merits are hyped and harms underplayed. Patients lack information on practice variation, the effectiveness of their care, and the extent of medical uncertainty. Practice is informed by an interventions. Discussion groups of patients, carers, and clinicians led by the James Lind Alliance in the United Kingdom, and the Patient Centered Outcomes Research Institute in the United States, are shedding light on the mismatch between the questions that patients and doctors want answers to and the ones that researchers are investigating. Joint discussions have helped build a database of uncertainties about the effects of treatment (www.library.nhs.uk/duets/).

Patients and doctors are also collaborating to design new services and information systems. Leaders in innovative partnership include ReshapeHealth (www.radboudreshapercenter.com), which is pioneering patient led and “crowdfunded” research. A growing number of healthcare organisations are giving patients access to, and in some cases control over, their medical records. At the Mayo Clinic a free app gives patients full access to their medical notes, pathology reports, and radiology reports; and because a shift in power depends on establishing a common lexicon, work is under way to reduce the medical jargon in these resources.

But partnering with patients must be seen as far more than the latest route to healthcare efficiency. It’s about a fundamental shift in the power structure in healthcare and a renewed focus on the core mission of health systems. We need to accept that expertise in health and illness lies outside as much as inside medical circles and that working alongside patients, their families, local communities, civil society organisations, and experts in other sectors is essential to improving health. Revolution requires joint participation in the design and implementation of new policies, systems, and services, as well as in clinical decision making.

Much remains to be discovered, evaluated, and implemented to achieve meaningful partnership with patients. There is also a need to embed shared decision making into routine practice. At an open meeting in June in Peru (www.isdm2013.org), which can be followed
Empowerment & some related concepts (MeSH)

There are some related concepts:

- **Patient Education (as Topic):** The teaching or training of patients concerning their own health needs (uncomplete).

- **Health literacy:** Degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (uncomplete)

- **Patient Participation:** Patient involvement in the decision-making process in matters pertaining to health.

- **Personal Autonomy:** Self-directing freedom and especially moral independence. Mosconi P. et al., 2012
Consumer Health Information vs Patient Education

- [....] Consumer health information (CHI) and patient education overlap in practice, since patient behavior may change as a result of receiving health information materials.

- Patient education and CHI often differ in terms of the setting in which the process occurs, rather than in terms of the subject matter...

Patient Education & Empowerment is the aim of a collaborative multicentric 3 years Research Project granted by the Italian National Health Authority.

Centro di Riferimento Oncologico of Aviano (CRO) is leading this project based on the program and activities of a local Patient Education & Empowerment Group (PEEG).
EXTENDING COMPREHENSIVE CANCER CENTERS EXPERTISE IN PATIENT EDUCATION: THE POWER OF PARTNERSHIP WITH PATIENT REPRESENTATIVES

Project Code:RF-2010-2308141

CRO, Aviano
Leader

BURLO, TS
partner

INT, Milano
partner

IOV, Padova
partner

Oncologico, Bari
partner

ASMN, Reggio Emilia
collaborator

AIMaC and ANGOLO (cancer patients associations) partner

Negri, Milano–
collaborator

IRST, Forlì –
collaborator

Cannizzaro Hospital, Catania
collaborator

Progetto di Ricerca Finalizzata, Ministero della Salute 2013-2015
The CRO PEEG (2010-) is a multi-professional, trans-disciplinary, non-hierarchical Work Team including patients, their representatives, and volunteers along with members of clinical, research and technical staff.

Its program is part of the CRO Annual Plan.
The role of the librarians

- The senior librarian, because of his competence in patient information, is the coordinator of this Team.

- A young librarian is the project manager of the collaborative Research Project (half time work)

- Another young librarian is involved in the surveys and networking

- The library is the pivot of patients' involvement.
The CRO Aviano (PN) is the North-Eastest Italian Cancer Comprehensive Center (1 out of 9): research & care & high education

✓ medium size
The Scientific & Patient Library

"Two libraries in one"
The program of the PEEG includes many different activities related to the areas of:

- Research
- Education, both patient and health care workers education
- Information & Communication
Nothing for the patients without patients

- To involve patients and their representatives in as many formal and informal situations as possible, where initiatives for patients are planned.

motto of the Cancer Patients Associations

“Nothing for the patients without patients”
Our hypothesis is that “patient empowerment”, i.e. the process of helping people to discover and use their own innate ability to gain mastery over their illness condition (operational definition, Crit Care Nurs Q. 2004, 27 (2): 201) cannot be effective if it doesn’t also mean:

- “doctors empowerment”
- “health care workers empowerment”
- “health care organisation empowerment” as health is like life, a complex matter
Our observations are based on

- the analysis of the free comments, discussions and narrations both of patients (pts) and Health Care Workers (HCW),
  but also

- on the periodical Reports of our Patient Education Activities drawn by the Lib-Coordinator
### Patient Education Activities 2013

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<tr>
<th>PEEG-Organizational meetings</th>
<th>Classes with patients about health topics</th>
<th>PE handout</th>
<th>National Literary Competition “Scriviamoci con cura” 2nd edition</th>
<th>Continuing Education Courses (CEC)</th>
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| 10 formal, but many other informal ad hoc meetings involving about 50 people – HCW, patients, volunteers... | 25 classes, about 30 HCW, expert patients and volunteers as teachers, about 15 topics such as:  
• “How to manage the adverse effects of chemotherapy”  
• “Eating well”  
• “Diet and cancer”  
• “How to deal with cancer emotions”  
• etc  
The topics are both proposed by the HCW and suggested by pts and relatives | 10 booklets involving 26 HCW as authors,  
- 6 people for the editing and  
- almost 30 patients as “reviewers” | 35 patients and HCW participated in as author-writers (39 only patients participants in 2012). (Part of a Narrative Medicine Global Program) | 25 out 195 CEC – ECM and not- (13%) were focused on improving the patient-physician relationship (Narrative Based Medicine etc...) vs 5% in 2012 |
Some preliminary results

- Important **increase of activities and participation** both of HCW and patients since 2011 until now,
  
e.g. pts participating to the classes: 50 (2011) vs 365 (2013)

- **Increase of the Library impact** on the organization/s

- **Change of priorities** as result of giving voice to the patients perspective
Lesson learned: HCW

- Health care workers (HCW):
  - About 30% of the HCW involved in this process had "enthusiastic insight" since the beginning of the program
  - Because of personal beliefs and/or
  - Previous experiences at international centres
Lesson learned

- about 30% of the HCW were quite sceptical at the beginning, e.g. not prepared for these kind of interactive mini-conferences during their daily care activities...

“I didn’t believe that there were in-treatment patients participating in these classes…”

“I don’t believe that a narrative approach is a dependable approach…”

“I didn’t believe so many people were interested in the diet and CAM topics…”
Lesson learned

– About 15% of HCW honestly participating in the different activities but apparently **scarcely involved** in the “cause” of the Patient Education & Empowerment process.

These classes are sometimes like a beautiful concert for a few auditors 😊

This is our diagnostic and clinical path and the patients have to accept it!

The attitude of these HCW is changing but this change is not an easy matter...
Lesson learned

– about 15% (of the HCW involved in the Patient Education & Empowerment process) feel their work as a “human adventure”, they like to know their patients as human before patients and to put themselves on the line.
Lesson learned:
The expert patient

Patients:

- **the expert patient, i.e.** the patient who decides to become expert and make available his own expertise, plays an important role in driving other patients.

**www.cignoweb.it** can help!!!
Lesson learned: The Librarian

- A biomedical librarian, expert in handling with consumer health information - and patient information & communication needs - can help both doctors, in “learning” from their patients, and patients in asking & understanding and searching & finding.

[www.cignoweb.it](http://www.cignoweb.it) can help both patients and librarians, public and health librarians, and HCW…
Lesson learned: The Librarian

- A biomedical librarian's expertise in the management of scientific literature can support patients in their need of a proper information but also help them get more cautious on certain controversial and deceptive issues.

www.cignoweb.it can help!!!
Lesson learned: The Librarian

- The librarian's **expertise in quality evaluation of the information for health consumers** (HonCode, ETHIC ©) is highly required as well as his/her attitude to effectively collaborate with other HCW

- He can be a powerful driver of the whole Patient Education process.

[www.cignoweb.it](http://www.cignoweb.it) can help!!!
Actually, our small group of librarians/information specialists working as “catalysers” noticed that:

1. Presentations by HCW/language more and more scientific & conversational

2. Doctors started to enjoy Talking with Patients in small groups and Patients Talking with Doctors

3. Controversial aspects are discussed

4. Patients priorities are respected (eg CAM and nutritional counseling, new drugs side effects etc)
Conclusions

So CHI librarian can

- help patients getting up from their knees
- facilitate doctors to reduce the traditional asymmetry
- Empower his/herself being active part of the whole process.

Thank you for your attention!

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