Patient education: who empowers whom?

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Biblioteca-Direzione Scientifica IRCCS CRO Aviano,(PN)
The focus of my speech is the concept of **Empowerment in practice**.

- Not from a medical point of view, but
- a biomedical & health consumers librarian and technical coordinator of the CRO Patient Education & Empowerment Group (PEEG), where patient representatives and volunteers are involved, directly reporting to the Scientific Director.
The Context www.cro.it

✓ The CRO Aviano (PN) is the North-Eastest of the Cancer Comprehensive Centers in Italy
✓ medium size
✓ 1 out of 9
The CRO PEEG is a multi-professional, trans-disciplinary, not hierarchical team, including doctors, nurses, health technicians, biologists, administration positions, librarians ...and, as essential components, patient representatives and volunteers.
This program includes many different activities related to the areas of

- Research
- Education, both patients and health care workers
- Information & Communication
Our first aim

- 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 representatives

“Nothing for the patients without patients”
Empowerment (power/Mesh) is a process...some related concepts

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

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

*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.

*Personal Autonomy:* Self-directing freedom and especially moral independence

Mosconi P. et al., 2012
Patient empowerment in theory and practice: Polysemy or cacophony?

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Received 3 July 2006; received in revised form 22 September 2006; accepted 22 September 2006

Abstract

Objective: This paper examines how the term “empowerment” has been used in relation to the care and education of patients with chronic conditions over the past decade.

Methods: Fifty-five articles were analysed, using a qualitative method of thematic analysis.

Results: Empowerment is more often defined according to some of its anticipated outcomes rather than to its very nature. However, because they do not respect the principle of self-determination, most anticipated outcomes and most evaluation criteria are not specific to empowerment. Concerning the process of empowerment, our analysis shows that (i) the educational objectives of an empowerment-based approach are not disease-specific, but concern the reinforcement or development of general psychosocial skills instead; (ii) empowering methods of education are necessarily patient-centred and based on experiential learning; and (iii) the provider–patient relationship needs to be continuus and self-involving on both sides.

Conclusion: Our analysis did not allow for the unfolding of a well-articulated theory on patient empowerment but revealed a number of guiding principles and values.

Practice implications: The goals and outcomes of patient empowerment should neither be predefined by the health-care professionals, nor restricted to some disease and treatment-related outcomes, but should be discussed and negotiated with every patient, according to his/her own particular situation and life priorities.

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“...the **goals and outcomes of patient empowerment** should **neither be predefined** by the health-care professionals, nor **restricted to some disease and treatment-related outcomes**, **but should be discussed and negotiated with every patient**, according to his/her own particular situation and life priorities”

Isabelle Aujoulat, University of Louvain

Patient Empowerment and Patient-Centeredness

The relation between patient-centeredness and patient empowerment: A discussion on concepts

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Received: January 27, 2009; Received in revised form: August 6, 2009; Accepted: August 12, 2009; Published Online: September 14, 2009

DO: http://dx.doi.org/10.1016/j.pec.2009.08.008

Abstract

Objective

The concepts of patient-centeredness and patient empowerment offer opportunities for patients to increase their autonomy and involvement in their care and treatment. However, these concepts appear to be understood in different ways by professional groups involved in healthcare and research. To optimize understanding there is a need to create a common language. To explore and compare the concepts of patient-centeredness and patient empowerment, and clarify a possible relationship between the two from the perspective of the encounter between patients and their healthcare providers.

Methods

Concept analysis approach in which the concepts are compared based on literature review.

Results

Patient-centeredness can be the goal of an encounter between patient and caregiver. As a process, it is of great value in the process of patient empowerment. Patient empowerment appears to be broader than patient-centeredness, and may place greater demands on caregivers and the organisation of healthcare.

Conclusion

Patient-centeredness and patient empowerment are complementary concepts which do not oppose one-another. Patient empowerment can be achieved by patient-centeredness, but patients can also empower themselves.

Practice implications

Clarification of patient-centeredness and patient empowerment can facilitate their use by those involved in healthcare, improve the quality of healthcare, and aid future research.
Let the patient revolution begin

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

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.radboudreshapcenter.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
…Robert Johnstone (of the International Association of Patients Organisation) 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…..”
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:

- “doctor empowerment”
- “health care workers empowerment”
- “health care organisation empowerment” as health is like life, a complex matter
Quali-quantitative method

Our method is 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 numerical Report of our Patient Education Activities
## Patient Education Activities 2013

<table>
<thead>
<tr>
<th>PEEG-Orginalizational 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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<tr>
<td>10 formal, but many other informal ad hoc meetings involving about 50 people – HCW, patients, volunteers...</td>
<td>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, 10 booklets involving 26 HCW as authors, - 6 people for the editing and - almost 30 patients as “reviewers”</td>
<td>10 booklets involving 26 HCW as authors, - 6 people for the editing and - almost 30 patients as “reviewers”</td>
<td>35 patients and HCW participated in as author-writers (39 only patients participants in 2012). (Part of a Narrative Medicine Global Program)</td>
<td>25 out 195 CEC – ECM and not- (13%) were focused on improving the patient-physician relationship (Narrative Based Medicine etc.) vs 5% in 2012</td>
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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)

- Organizational impact

- Change of priorities
Lesson learned

- HCW: about 30% of the health care workers 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, 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% honestly participating in the different activities but apparently scarcely involved in the “cause” of the Patient Education & Empowerment.

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 rapidly changed but this change was 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 role of the expert patient, i.e. the patient who decides to become expert and make available his own expertise, is essential.
- He can be a powerful driver of the Patient Education process.

www.cignoweb.it can help!!!
Actually, our small group of 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, nutritional counseling, new drugs side effects etc)
5. ...
Conclusions

In the field of medicine and allied sciences, the shift from the past “paternalistic approach” to the current collaborative one, will be only really done when patients and doctors meet together as humans.
Conclusions

❖ Patients don’t want their doctors to know everything, but they are expert in their own fields, networked with other experts, interested in knowing from them what is important to know, aware of the impact of their words and behaviour.

❖ Patients empower themselves, also learning to share responsibilities with their doctors.
So, who empowers whom?

BOTH

- HCW empower patients and
- patients empower doctors/HCW...
- BOTH empower the healthcare organisations/system...

Thank you for your attention!

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