PATIENT EDUCATION AND EMPOWERMENT: THE EXPERIENCE OF AN ENLARGED WORKING GROUP?

P. DE PAOLI for the Extending CCCs expertise in Patient Education: the power of partnership with patient representatives
THE DELIVERY OF HIGH QUALITY CANCER CARE  
(Ganz and Levit JCO 31, 4485, 2013)

<table>
<thead>
<tr>
<th>Table 1. Goals of the Recommendations</th>
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</thead>
<tbody>
<tr>
<td>1. Provide patients and their families with understandable information about cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and costs.</td>
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<tr>
<td>2. Provide patients with end-of-life care that meets their needs, values, and preferences.</td>
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<tr>
<td>3. Ensure coordinated and comprehensive patient-centered care.</td>
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<tr>
<td>4. Ensure that all individuals caring for patients with cancer have appropriate core competencies.</td>
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<tr>
<td>5. Expand the breadth of data collected in cancer research for older adults and patients with multiple comorbid conditions.</td>
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<td>6. Expand the depth of data collected in cancer research through a common set of data elements that capture patient-reported outcomes, relevant patient characteristics, and health behaviors.</td>
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<tr>
<td>7. Develop a learning health care information technology system for cancer that enables real-time analysis of data from patients with cancer in a variety of care settings.</td>
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<tr>
<td>8. Develop a national quality reporting program for cancer care as part of a learning health care system.</td>
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<tr>
<td>9. Implement a national strategy to reduce disparities in access to cancer care for underserved populations by using community interventions.</td>
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<tr>
<td>10. Improve the affordability of cancer care through existing efforts to reform payment and eliminate waste.</td>
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</tbody>
</table>
PATIENT EDUCATION: THE TEACHING OR TRAINING OF PATIENTS

To increase the educational competence of a large number of cancer patients and to **improve their health status**, based on the results of surveys on health literacy, characteristics (age, gender, etc) and expectations of the patients admitted to Italian Comprehensive Cancer Centers. **Patients must be active part of the process.**

- Il [1] Patient Education: *The teaching or training of patients concerning their own health needs* (Fonte: PubMed/MeSH)
- Patient Education Handout: Works consisting of a handout or self-contained informative material used to explain a procedure or a condition or the contents of a specific article in a biomedical journal and written in non-technical language for the patient or consumer (Fonte: PubMed/MeSH)
- Educational Models: Theoretical models which propose methods of learning or teaching as a basis or adjunct to changes in attitude or behavior. These educational interventions are usually applied in the fields of health and patient education but are not restricted to patient care. (Fonte: PubMed/MeSH)
- Decision Aids: Interventions designed to help people make specific and deliberative choices among options by providing information about the options and outcomes that is relevant to a person’s health status (Cochrane DBSR)
PATIENT EDUCATION AT CRO AVIANO

- A PE group has been appointed in 2010
- Multidisciplinary, multiprofessional including patients’ representatives

ACTIVITIES:
- Research
- Information
- Education
- Improve health care in oncology
PATIENT EDUCATION/EMPOWERMENT (PE)
IN ITALIAN CCCs

**CRO, Aviano** – Principal Investigator

**IRST, Forlì** – collaborator

**ASMN, Reggio Emilia** – collaborator

**BURLO, TS** – partner

**IOV, Padova** – partner

**INT Milano** – partner

**Oncologico, Bari** – partner

**Negri, Milano** – collaborator

**PASCALE Napoli**

**IST SAN MARTINO, Genova**

* Ospedale Cannizzaro CT

Progetto di Ricerca Finalizzata, Ministero della Salute 2013-2015
AIMS

• To establish in each center a PE committee and a PE “ad hoc” program
• To work out operational tools for patient information/education
• To improve access to information through traditional and innovative tools
• To establish independent Medicines Information Centres
• Propose a training curriculum in PE for health care providers and for volunteers
• Obtain info on health literacy and patients’ expectations concerning PE
STUDY DESIGN

- WP1 From health literacy to information services: planning the program, CRO Aviano
- WP2 Clinical trials, informed consent, INT Milan
- WP3 Independent info on medicines, CRO Aviano
- WP4 Personalized information: a program for pediatric patients, Burlo Garofolo Triest
- WP5 How to educate the educators, AIMaC Rome
- WP6 Educational programs for health care providers, Oncologico Bari
- WP7 Traditional and new tools to deliver the educational material, IOV Padua
CROinforma è la collana di informazione divulgativa del Centro di Riferimento Oncologico di Aviano, rivolta a pazienti e cittadini. Tratta argomenti inerenti alla ricerca, prevenzione, cura dei tumori.


Si articola in diverse serie: LA RICERCA CHE CURA; INFORMAZIONI SCIENTIFICHE; PERCORSI DI CURA; ISTRUZIONI ALL’USO DL.; AREA GIOVANE; CIFA INFORMAZIONE SUL FARMACO

Tutte le pubblicazioni di questa collana sono disponibili presso la Biblioteca del CRO di Aviano

.... molte altre pubblicazioni in fase di realizzazione
“Classes” with patients and caregivers

“Thematic issues” based on patients’ requests
Extending comprehensive cancer centers Expertise in patient education: the Power of Partnership with patient representatives

Project Code:RF-2010-2308141

WP2 – Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (Dott. Marco Pierotti)
Clinical trials and informed consent.

The aim of this WP:
“To work out operational tools for the process of patient information in clinical studies based on an analysis of ethical and legal requirements on one side and clinical and psychological needs on the other. The process should be acceptable to all the stakeholders involved in the process (patients, regulators, clinical trial sponsors) and be clinically and psychologically sound at the same time”
WP 5 di AIMaC: Educating the Educators

Educational courses: Milano 19-22 maggio; Roma 26-29 maggio; Napoli 9-12 giugno.
Online tools: Aprile – giugno 2014
Extending comprehensive cancer centers expertise in patient education: the power of partnership with patient representatives

WP7
Traditional and New Tools to Deliver the Educational Material

From patients to partners: participant-centric initiatives in biomedical research


Abstract | Advances in computing technology and bioinformatics mean that medical research is increasingly characterized by large international consortia of researchers that are reliant on large data sets and biobanks. These trends raise a number of challenges for obtaining consent, protecting participant privacy concerns and maintaining public trust. Participant-centred initiatives (PCIs) use social media technologies to address these immediate concerns, but they also

Social media!
**MY EXPERIENCE**

Ultimo aggiornamento Mercoledì, 27 Novembre, 2013 19:49 Scritto da marina

Il Sito **MyExperience** nasce dalla volontà di creare uno "spazio" dedicato alle persone che vivono l'esperienza di malattia oncologica, a livello personale e/o familiare, e la decisione di sottoporsi ad un'indagine genetica.

Addentrandosi nel campo dell'oncologia, e nello specifico dei tumori ereditari, si rischia di reperire molte informazioni, spesso confuse e spiegate (pur troppo) in termini troppo complessi.

Noi vorremmo offrirti l'opportunità di conoscere più nel dettaglio le sindromi genetiche [vedi: CONSULENZE GENETICHE] che trattiamo, cercando di esser chiarì ed utilizzando un lessico semplice pur non trascurando la rilevanza dei temi trattati.

Potrai chiederci tutto quello che ritieni più opportuno, come ad esempio: maggiori chiarimenti, ulteriori informazioni su un tema che hai letto o che non sei riuscito a comprendere; suggerimenti degli approfondimenti...

Inoltre, potrai compilare i **questionari** [vedi: HO I REQUISITI?], a seconda della neoplasia di cui sei affetto (o è affetto un tuo familiare), che ti permettono di comprendere se la tua storia personale e familiare, di malattia oncologica, possa essere legata ad aspetti genetici. Noi vogliamo offrirti l'opportunità di poter esprimere i tuoi dubbi e la tua opinione.

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**RIESENZA NEL SITO**

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**RACCONTA LA TUA STORIA**

**HO I REQUISITI PER EFFETTUARE UN'INDAGINE GENETICA?**

- **NEOPLASIE EREDO-FAMILIARI COLON RETTO**
- **NEOPLASIE NEURO/ENDOCRINE EREDITARIE**
- **NEOPLASIE EREDO-FAMILIARI MAMMELLA-OVAIO**
Personalized information: a program for pediatric patients
Marco Rabusin, Laura Pomicino, Sara Buchini, Antonella Longo
L’Educazione Terapeutica del paziente oncologico sul buon uso dei farmaci

(un anno dopo)
PATIENT EDUCATION: NOT ONLY PATIENTS!
INVOKE HEALTH CARE WORKERS!

- HCWs must fulfill the requirements of the patients and of their organization.

- Cancer patients determine a strong emotional involvement.

- Team working and individual needs: tailoring education.

- Develop hcw communication skills to fully realize patient centered care.
Narrative Medicine at CRO
National Cancer Institute in Aviano, Italy

- Major Italian Cancer Research Center
- “Patient Education,”* since 2010, & other educational Programs
- Annual NM conferences since 2011.

*Extending comprehensive cancer centers expertise in patient education: the power of partnership with patient representatives. Ricerca Finalizzata finanziata dal Ministero della Salute
PATIENT EDUCATION/EMPOWERMENT (PE)

A Survey In Italian Comprehensive Cancer Centers

• 4 KEY POINTS CPEN (Cancer Patient Education Network)
  • http://www.cancerpatienteducation.org/

• 1. PE as a cancer priority
• 2. activities included in PE programs
• 3. involvement of patients and caregivers
• 4. involvement of health care workers

Progetto di Ricerca Finalizzata, Ministero della Salute
PATIENT EDUCATION/EMPOWERMENT (PE) IN ITALIAN CCCs

PE is a institutional, shared, priority

PE is realized on a spontaneous, non coordinated basis

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4 (36.4%)</td>
</tr>
<tr>
<td></td>
<td>7 (63.6%)</td>
</tr>
</tbody>
</table>

Which activities do provides the PE program?

<table>
<thead>
<tr>
<th></th>
<th>classes</th>
<th>PE handout</th>
<th>Info point</th>
<th>CME</th>
<th>Wellness classes</th>
<th>Support for caregivers</th>
<th>mutual support</th>
<th>volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10 (91%)</td>
<td>10 (91%)</td>
<td>7 (64%)</td>
<td>9 (82%)</td>
<td>9 (82%)</td>
<td>8 (73%)</td>
<td>8 (73%)</td>
<td>10 (91%)</td>
</tr>
<tr>
<td>No</td>
<td>1 (9%)</td>
<td>1 (9%)</td>
<td>3 (27%)</td>
<td>2 (18%)</td>
<td>2 (18%)</td>
<td>3 (27%)</td>
<td>3 (27%)</td>
<td>1 (9%)</td>
</tr>
</tbody>
</table>

Progetto di Ricerca Finalizzata, Ministero della Salute 2013-2015
<table>
<thead>
<tr>
<th>PE activities</th>
<th>classes</th>
<th>PE handout</th>
<th>Info point</th>
<th>CME</th>
<th>Wellness classes</th>
<th>Caregivers</th>
<th>groups of mutual support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>8 (73%)</td>
<td>7 (70%)</td>
<td>6 (55%)</td>
<td>4 (44%)</td>
<td>6 (55%)</td>
<td>6 (75%)</td>
<td>4 (37%)</td>
</tr>
<tr>
<td>No</td>
<td>1 (9%)</td>
<td>3 (30%)</td>
<td>/</td>
<td>/</td>
<td>2 (18%)</td>
<td>2 (25%)</td>
<td>2 (18%)</td>
</tr>
<tr>
<td>Nr</td>
<td>2 (18%)</td>
<td>5 (45%)</td>
<td>/</td>
<td>/</td>
<td>3 (27%)</td>
<td></td>
<td>5 (45%)</td>
</tr>
</tbody>
</table>
## PATIENT EDUCATION/EMPOWERMENT (PE) IN ITALIAN CCCs

### Involvement of health care workers in the organization of PE

<table>
<thead>
<tr>
<th>Type of personnel</th>
<th>classes</th>
<th>Continuing learning</th>
<th>Wellness classes</th>
<th>Support caregivers</th>
<th>groups of mutual support</th>
</tr>
</thead>
<tbody>
<tr>
<td>administratives</td>
<td>8 (80%)</td>
<td>/</td>
<td>1 (11%)</td>
<td>1 (12%)</td>
<td>0</td>
</tr>
<tr>
<td>Doctors</td>
<td>6 (60%)</td>
<td>7 (78%)</td>
<td>4 (44%)</td>
<td>5 (62%)</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>Nurses</td>
<td>5 (50%)</td>
<td>4 (44%)</td>
<td>3 (33%)</td>
<td>5 (62%)</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>Librarians</td>
<td>3 (30%)</td>
<td>2 (22%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>pharmacists</td>
<td>2 (20%)</td>
<td>/</td>
<td>/</td>
<td>/</td>
<td>/</td>
</tr>
<tr>
<td>outsourcing</td>
<td>2 (20%)</td>
<td>0</td>
<td>0</td>
<td>/</td>
<td>/</td>
</tr>
<tr>
<td>psychologists</td>
<td>/</td>
<td>7 (78%)</td>
<td>8 (89%)</td>
<td>7 (87%)</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Training office</td>
<td>/</td>
<td>9 (100%)</td>
<td>/</td>
<td>/</td>
<td>/</td>
</tr>
<tr>
<td>Volunteers – patients</td>
<td>/</td>
<td>3 (33%)</td>
<td>7 (78%)</td>
<td>4 (50%)</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Communication office</td>
<td>/</td>
<td>2 (22%)</td>
<td>/</td>
<td>/</td>
<td>/</td>
</tr>
<tr>
<td>other (experts)</td>
<td>/</td>
<td>/</td>
<td>6 (66%)</td>
<td>1 (12%)</td>
<td>/</td>
</tr>
</tbody>
</table>
Information Needs of Cancer Patients

- Diagnosis explanation: 308
- Early diagnosis: 281
- Prevention: 274
- Side effects: 193
- Nutrition for specific neoplasms: 168
- Chemotherpay: 168
- Clinical trials: 151
- Palliative cares: 122
- Cancer and sexuality: 114
- Services management: 98
- Postoperative Period: 97
- Conventional treatments: 94
- Radiotherapy: 86
- Drugs: 81
- Complementary therapies: 79
- Patients' rights: 64
- Nutrition (generic): 62
- Nutrition and therapies: 43
- Side effects: 29
- Leisure activities for inpatients: 22
- Other: 13

Progetto di ricerca finalizzata Patient Education
Information needs of parents of children with cancer

- Long term side effects: 29
- Side effects: 27
- Treatments outcomes: 27
- Diagnosis explanation: 26
- Treatment options for their sons: 24
- Information concerning expectation during treatments: 22
- New therapies: 19
- Complete healing chances: 14
- Psychological support for parents: 11
- Psychological support for patients: 11
- Bureaucratic informations: 9
- Explanation of information about treatments delivered by healthcare: 8
- Psychological support for patient's brothers/sisters: 6
- Explanation of information about patient care management delivered: 6
- Educational support: 5
- Information concerning diet delivered by healthcare professionals: 5
- Psychological support for patient's brothers/sisters: 5
- Logistic informations: 3
- Ward operation: 2
- Fertility preservation: 2
- Support facilities available in the district (volunteers associations...): 0
- Assisted living facilities: 0

Progetto di ricerca finalizzata Patient Education
Survey on functional Health Literacy in groups of cancer patients and caregivers:

Italian version of S-TOFLHA, NVS and single question tools validation study.

Observational prospective multicentric study.

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Establishing Comprehensive Cancer Patient Education Programs: Standards of Practice
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- A. Conficconi (IRST Meldola)
- F. De Lorenzo, A. D’Acunti (AIMAC)
IL CRO: LA RICERCA CURA
Perché “PATIENT EDUCATION”?

NON si tratta di “far stare educati” i pazienti… NE’ solo di educazione terapeutica: operatori che istruiscono i pazienti (vecchia concezione…)

- CONCETTO COMPLESSO E IN EVOLUZIONE

- Processo sostanzialmente biunivoco: gli operatori insegnano ai pazienti, ma al contempo “imparano” dai pazienti ciò che “serve” del punto di vista e viceversa

by Liceo Artistico-Istituto Galvani di Cordenon s 2012
The Trilateral Approach: 3 NM Venues

- Fairy tale Seminars
- Narrative Medicine Workshops
- Philosophy Seminars
PATIENT EDUCATION/EMPOWERMENT (PE) IN ITALIAN CCCs

- **CLASSES**: meetings on cancer types where doctors, nurses, psychologists, etc. meet patients.
- **PE HANDOUT**: educational material.
- **CIS (Cancer Information Service)**: Continuous Medical Education on specific PE themes.
- **WELLNESS CLASSES**: gym, cooking, make up training for cancer patients, etc.
- **SUPPORT FOR CAREGIVERS**
- **GROUPS OF MUTUAL HELP AND SUPPORT**
- **VOLUNTARY ASSOCIATIONS**
IMPACT

- A stable PE program in each CCC is expected to impact on patients' behaviour and health status.
- Patient centered educational tools (with the patients, adapted to specific needs of the CCCs participating to the project).
- High quality educational tools for patients and more opportunities to access.
- Educational material dedicated to innovative topics (not covered by other actors in cancer care) that are related to the mission of CCCs.
- Dynamic project evolving according to periodical assessments.