CONGRESSO NAZIONALE

IX APPUNTAMENTO AINAT - I SIN
GRUPPO DI STUDIO NEUROLOGIA
DEL TERRITORIO

"IL NEUROLOGO TRA PREVENZIONE,
ASSISTENZA E COMPLESSITÀ,
FRAGILITÀ, NON AUTOSUFFICIENZA
DELLE MALATTIE
NEUROLOGICHE CRONICHE"

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OTTOBRE
2015

Monopoli (BA)
Hotel Vecchio Mulino
Viale Aldo Moro, 192

produrre salute

Sistema Integrato per la Revisione dei Modelli di Intervento Socio-sanitario, Ambientale e sulla Sicurezza

Le associazioni dei pazienti 2.0

Innovazione nel ruolo di supporto informativo e tecnologico al servizio degli assistiti

dott.ssa Esther Paola Tattoli
Presidente A.P.M. Produrre Salute

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1 Cosa è una Associazione 2.0
2 La transizione epidemiologica
3 I nodi del cambiamento
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Cosa è una Associazione 2.0

- È una organizzazione **indipendente e diretta dagli utenti**
- È il soggetto che **individua ed esprime gli stati di bisogno reale**
- È capace di **produzioni autonome ed originali**
- **Opera in rete** con tutti gli *stakeholders* affini e/o complementari
- Effettua la **raccolta e la sintesi delle esperienze** sul campo
- È il soggetto che **legittima e dà valore ai servizi offerti**

Cosa è una Associazione 2.0

BMJ

BMJ 2013;346:f1990 doi: 10.1136/bmj.f1990 (Published 2 April 2013) Page 1 of 3

ANALYSIS

ESSAY

How the e-patient community helped save my life: an essay by Dave deBronkart

Dave deBronkart—otherwise known as e-Patient Dave—describes his four year odyssey from cancer diagnosis to international patient superstar. His journey shows the contribution that patients can make to the complexities of medicine

Dave deBronkart *policy adviser on patient engagement*

Nashua, New Hampshire, USA

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It was the start of an improbable odyssey, leading to speaking engagements at 200 meetings, a Salzburg global seminar on shared decision making, co-chairmanship of the Society for Participatory Medicine, testimony on government policy, events in many countries, and a TEDx talk[3] that is in the top half of most viewed ever and has subtitles in 26 languages. Time and again I find myself wondering what people have heard that draws such interest; I wouldn't have been so bold as to predict it.

I think it is because, although I understand science—I love it, and I'm alive because of it—I also sense a substantial disconnect between what patients value and what medicine offers. And this raises the question: we all agree medicine should provide value for money, but who gets to say what value is?

This is not anti-doctor

I was saved by brilliant science and top notch clinicians. Diagnosed incidentally with stage IV, grade 4 metastatic renal cell carcinoma, I had bone metastases in my femur (which eventually fractured), ulna, and cranium; five metastases in my lungs; and muscle metastases in my thigh and tongue. Yet six months after diagnosis my treatment ended: I've not had a drop of anything since. A superb surgeon removed my kidney and adrenal gland; another repaired my femur (twice), and a skilled oncology team tended me through a difficult and dangerous treatment. Today I am well.

My gratitude goes out to every person who worked on development of the drug and the new protocol I received. Thank you to science, and to every clinician whose training and experience led them to be in the world class team at Beth Israel Deaconess Medical Center that saved my life. My family add their thanks.

What is value and who provides it?

What does my experience tell us about value? To understand a changing industry we must be clear about the elements that constitute value in medicine. Clearly, my team's achievements are valuable. Let's list some:

Awareness of status—I had no idea I was sick; I'd been tired and slowly losing weight, but at age 56 neither seemed a problem. I was unaware of my cancer until doctors spotted a shadow in my lung during a routine shoulder x ray examination.

Accurate diagnosis—Radiology quickly suggested renal cell carcinoma, but my doctors didn't leap to a plan until a biopsy made it certain.

Current information on treatment options—I've since learnt that three out of four patients with metastatic renal cell cancer never hear of the treatment I got, high dosage interleukin-2 (IL-2). At the time it was the only drug that sometimes produced this result.

Surgical excellence—I was so sick that my nephrectomy had to be laparoscopic, which offers quicker recovery so the IL-2 could start. My surgeon says he almost had to fall back to open surgery. His skill was valuable. As was that of the orthopaedic surgeon: my leg works. I am repaired.

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Le società dei paesi sviluppati sono costrette oggi ad affrontare valutazioni importanti e ridimensionamento dei costi – in particolare riflettendo su ciò che è o crea valore. I governi non possono prendere da soli queste decisioni, e neppure il personale sanitario: come nell'industria il valore viene definito da colui che fruisce o meno del servizio erogato, così per la sanità il paziente dovrebbe partecipare ai processi decisionali sulle politiche sanitarie

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Gli strumenti online di supporto ai pazienti con malattie croniche o acute sono risorse preziose: infatti mentre "*i medici devono tenersi aggiornati su un'ampia varietà di patologie, e farlo mentre visitano decine di pazienti al giorno; i pazienti invece tipicamente conoscono solo loro una malattia, ma dal momento che sono costretti a dedicarci molto tempo, le loro conoscenze su quello specifico argomento possono essere molto approfondite*"

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Informazioni ***"non istituzionali"*** sulle patologie e sull'assistenza sanitaria possono avere un valore enorme per i pazienti, e possono migliorare molto la loro esperienza di assistenza.

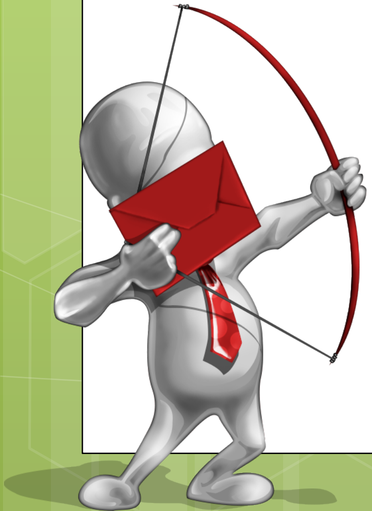
Un paziente informato (un "paziente 2.0") è quindi una risorsa preziosa per il sistema sanitario, e un potenziale produttore di valore per altri pazienti.

La transizione epidemiologica

- Il sistema è sempre più **isorisorse**
- La **transizione epidemiologica dall'acuzie alla cronicità** ci obbliga a confrontarci con una stringente ed inevitabile modificazione della *visione ospedalocentrica* dell'assistenza.
- In un contesto di pandemie a carattere cronico-recidivante e degenerativo **la prevenzione ed il supporto di sistemi tecnologicamente avanzati di diagnosi, cura e assistenza,** occupano un posto rilevante nel controllo tanto delle fasi di riacutizzazione, quanto della stessa insorgenza precoce e incontrollata dello stato patologico e di malattia.

I nodi del cambiamento

- La **partecipazione degli utenti ai processi decisionali relativi all'implementazione di modelli pluridisciplinari innovativi**, riguardanti la nosologia e l'epistemologia degli stati patologici (con appropriato inquadramento della loro eziologia e patogenesi), con particolare riferimento alla *transizione dal paradigma riduzionistico a quello olistico* e al riconoscimento e all'adozione della *medicina regolatoria-sistemica,* indispensabile per l'intervento sul sistema bersaglio.



- L'adozione delle **conoscenze più appropriate** non utilizzate e la loro **implementazione in termini translazionali**.
- La **presa in carico dei pazienti da parte di *equipe* plurispecializzate nel connubio ospedale-territorio**, che possano risolvere i limiti e gli anacronismi della monospecialità.

Azioni da compiere

- **Istituzione di un tavolo permanente della programmazione sanitaria regionale**, composto da tre elementi fondamentali: gli utenti esperti ed organizzati in consessi associativi; gli attori di settore (pubblici e privati); gli amministratori pubblici.
- **Inserimento delle Associazioni 2.0 degli utenti** nei consessi politico-amministrativi, nei tavoli tecnici e nei gruppi di lavoro **con potere di pianificazione e parere vincolante**.
- **Armonizzazione e integrazione,** tra ambito pubblico e privato, **dei sistemi di assistenza e cura, oltreché di monitoraggio e valutazione delle performance** degli operatori e dei processi, con conseguente **realizzazione di un sistema misto e integrato**.

produrre
salute

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GRAZIE

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