

The Cochrane Consumer Network and the WHO/ Patients for Patient Safety

Silvana Simi

Cochrane Collaboration Consumer Network

WHO/PFPS

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NEW STATEMENT OF PATIENTS' RIGHTS:

***“You have the Right to remain silent.
Anything you say can and will be used against you.”***

From 'The Onion Newspaper': <http://www.theonion.com>

On the contrary, patients have to give voice to their ideas, as they

- are the only ones entitled to their health
 - have the right to have their will and experience respected
 - can bring to the table a valuable perspective which comes from being the receiving end of health services
 - can determine new directions and priorities
 - can focus on issues that researchers are not aware of
 - are markers of how services are working

addressing the needs and preferences of patients, is a fair and most cost-effective way to improve health outcomes

A metaphor:

Patient Education and Counseling 62 (2006) 288–290

www

The flat-pack patient? Creating health together

Harry Cayton

Department of Health, Richmond House 79, Whitehall, London SW1A 2NS, UK

- IKEA: sells flat-pack furniture
 - CUSTOMER: carries it home and assembles it himself
 - IKEA: saves space, time, money and can reduce its prices
 - CUSTOMER: becomes a partner in the manufacturing process and is happy to invest time and efforts in his home.
-
- Flat-pack patient : contributes to define, implement and co-create his own health and health service
 - A win-win situation

Euro Health Consumer Index: a country I know well



The Euro Health Consumer Index (2009) ranks Italy : " technically excellent in many places, but poor geographical equity. Autocratic attitude from doctors prevents Italy from scoring high in a consumer index. A power shift to patients necessary".

Two international organizations:



- The Cochrane Collaboration

The aim of any medical care is to benefit patients. The best person to judge whether any healthcare intervention has been beneficial is the patient (from the website)

[http:// www.cochrane.org](http://www.cochrane.org)



- World Alliance for Patient Safety

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care (WHO/Alma Ata 1978)

<http://www.who.int/patientsafety/en/>

<http://consumers.cochrane.org/>



Cochrane Consumer Network

ccnet

Helping consumers access the best evidence in healthcare

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⇒ More than 700 consumers from 50 countries

From the Cochrane Manual:

3.4.8 The Consumer Network

The Cochrane Consumer Network ([CCNet](#)) supports consumer participation within The Cochrane Collaboration. Registered with The Cochrane Collaboration in October 1995, the Consumer Network encourages consumer involvement within The Cochrane Collaboration's range of activities.

People with consumer perspectives play an integral and unique role in many aspects of The Cochrane Collaboration's work. Their perspectives particularly influence:

1. Descriptions of the full range of benefits, problems and ethical issues of healthcare interventions and the clinical trials that determine the usefulness of these interventions;
2. The ready accessibility and ease of understanding of Cochrane reviews for a wide range of readers, particularly the general public;
3. The role that consumer advocacy organisations can play in promoting the use of Cochrane reviews by the general public

The aims of the Consumer Network are:

1. To support both consumers and the Cochrane entities who seek the participation of consumers;
2. To make Cochrane reviews easy to understand and accessible to the general public;
3. To increase public awareness about the importance of: synthesizing evidence from clinical trials, as in Cochrane reviews; registering ongoing clinical trials so that the information is readily accessible to consumers and review authors who synthesise the findings; being transparent about the protocols of clinical trials and enrolment status.

- Accessibility and promotion of Cochrane reviews to the general public
- Consumers perspectives in peer-reviewing the Cochrane reviews
- Special attention to PLS

Natalizumab for relapsing remitting multiple sclerosis

Review information

Authors

Eugenio Pucci¹, Giorgio Giuliani¹, Alessandra Solari², Silvana Simi³, Silvia Minozzi⁴, Carlo Di Pietrantonj⁵, Ian Galea⁶

¹U.O. Neurologia - Ospedale di Macerata, ASUR Marche - Zona Territoriale 9, Macerata, Italy

²Neuroepidemiology Unit, Fondazione I.R.C.C.S. - Neurological Institute Carlo Besta, Milan, Italy

³Past Senior Researcher of Institute of Clinical Physiology, Pisa, Italy

⁴Department of Epidemiology, ASL RM/E, Rome, Italy

⁵Servizio Regionale di Riferimento per l'Epidemiologia, SSEpi-SeREMI - Cochrane Vaccines Field, Azienda Sanitaria Locale ASL AL, Alessandria, Italy

⁶Division of Clinical Neurosciences, School of Medicine, University of Southampton, Southampton, UK

Plain language summary

The use of the monoclonal antibody Natalizumab (NTZ) in patients with relapsing remitting multiple sclerosis (RRMS)

It is currently thought that inflammation is crucial in MS, leading to a disruption in the ability of nerves to conduct impulses. NTZ is the first of a new generation of anti-inflammatory treatments for MS, which is given intravenously every 4 weeks. It is usually prescribed once other drugs have failed or when the disease is rapidly worsening.

The Authors of this review evaluated the efficacy, tolerability and safety of NTZ in patients with RRMS. Among the pertinent literature, 3 studies met the inclusion criteria of methodological quality, comprising a total of 2223 participants. The results show that NTZ treatment reduces the number of patients who experienced relapses and the number of patients who progressed at 2 years. Also Magnetic Resonance scans show evidence of a beneficial effect of NTZ on disease activity.

Although information on adverse events (AEs) was limited, as most participants were followed up for 2 years only, infusion reactions, anxiety, sinus congestion, lower limb swelling, rigors, vaginal inflammation and menstrual disorders were found to be more frequent after NTZ treatment. However, the number of patients experiencing at least one AE (including severe or serious AEs) did not differ between NTZ and control groups. On the contrary, significant safety concerns have been raised regarding Progressive Multifocal Leukoencephalopathy (PML), a rare and often fatal viral disease characterized by damage to the white matter of the brain. In the studies included in this review, PML was reported in 2 patients treated with NTZ for more than 2 years. However, our protocol was insufficient to evaluate PML risk as well as other potential rare and long-term AEs (e.g. cancers and other infections) which are important issues in considering the risk/benefit ratio of NTZ. An independent systematic review of the safety profile of NTZ is warranted. NTZ should be used only by skilled neurologists in MS centres under surveillance programs.

All the data in this review came from studies supported by the Pharmaceutical Industry. In agreement with the Cochrane Collaboration policy, this may be considered a potential source of bias.

From the Cochrane Consumer Network (CCNet) Executive: a 2011 report

7. **Work in progress**

Work continues in the areas of training, communications with special attention to not-English first language people, global involvement, consumer integration and consumer support.

- Allen & Clarke 2009:
 - over 22.000 people from 103 countries
 - 96/103 countries are not English first language
 - English speaking people are over represented at all levels:
of the CC, 14/17 SG member are English-first language
- ➔ *to create strategies aimed at addressing this imbalance*

Putting Patient Safety on the World's Agenda, October 2004:

WHO/ Patients for Patient Safety

Safety will be improved if patients are included as full partners in reform initiatives, and learning can be used to inform systemic quality and safety improvements.

Main goals:

Coordination and acceleration of international improvements in patient safety.

Ensuring the perspective and viewpoint of patients, families and healthcare consumers in developed and developing countries.

Work in such areas as: research, reporting and learning, designing and implementing solutions, classification for patient safety and global patient safety challenges.



World Health Assembly, 2002

*'...Urging member states to pay
the closest possible attention
to...patient safety...'*

First Patients for Patient Safety workshop/ London 27-30 Nov 2005 :



24 participants selected through an international call for applications from 20 countries of the six geographical regions of WHO

Achievements: Formation of a global Patient Voice – London Declaration

In five years time :

PFPS 2005 - 2010

A Global Network

214 Champions from 51
countries

15 workshops, 11 countries, 600
participants and 7 in-country
networks



World Health
Organization

Patient Safety

A World Alliance for Better Health Care

Patient Safety Champions' activity:



- Patients Organizations
- Training Courses
- Media Campaigns
- Networking
- Journal Articles
- Patient Materials

Presentations to

- Healthcare workers
- Medical Students
- Patients
- Hospital boards
- National groups
- Health Ministers

Committees

- Health quality and hospital boards
- Health ministries
- WHO expert committees

Susan Sheridan, PFPS Chair, USA

Modern Healthcare Magazine, one of America's most well respected trade publications, has named Susan Sheridan, Patients for Patient Safety External Lead, to their list of the Top 25 Women in Healthcare for 2009. Key players in the movement to reform the nation's healthcare system dominate the list, and the programme honours women making a positive difference in the healthcare industry.



Sue one of the 25 American women who made a difference in healthcare

Rebecca O' Malley, PFPS Champion, Ireland



Rebecca: invited as member of the ‘Commission on Patient Safety and Quality Assurance’, set up by the Irish Minister for Health.

“Health chiefs should learn from their mistake, or else step aside”