

Cancer on the Internet 3rd International Conference

Washington, July 9-10. 2006
Ex New Orleans, September 8-9, 2005

Session: evaluating the effectiveness of online support

TITLE: Azalea: effectiveness as result of interaction between virtual and physical resources

AUTHORS: G. Cognetti¹, A. Bogliolo², W. Russell-Edu³, K. Bianchet⁴ and I. Truccolo⁴

AFFILIATIONS: 1Regina Elena Cancer Institute (IRE), Rome, Italy, 2 National Cancer Research Institute (IST), Genoa, Italy, 3 European Institute of Oncology (IEO), Milan, Italy, 4 National Cancer Institute, Oncology Referral Centre (CRO), Aviano, Italy

Are the resources available online sufficiently effective to guarantee information on the health of patients and their families? In order to be effective information has to be applied to a process of communication, thereby serving to establish a relationship¹. Therefore, information and communication have to be 'demassed'² and personalized. But how can this be adapted to electronic systems on the Internet?

It is necessary to highlight the various factors that reduce effectiveness of information on the Internet: it is often poorly organized, the documents retrieved by search engines are often of little use or poor quality, information/knowledge is not always integrated, even on more structured databases, the communicative style of the documents for patients may not be suited to that particular patient in their specific phase of illness.

The sub-optimal information thus retrieved may therefore determine or even increase the state of anxiety³.

Last but not least: linguistic barriers are still an obstacle to the use of optimal information, and, a large proportion of the population does not use Internet at all (Internet Divide), or uses it in an unsatisfactory way.

Azalea originated in a non-virtual project: the first nucleus of its database was the catalogue, physical and online, of the "Library for patients", a pilot project founded in 1998 at the Oncological Referral Center (CRO) of Aviano (one of the 7 Italian Scientific Institutes for Research, Hospitalization and Health Care, IRCCS), in order to meet in a qualified way the information needs of patients, their relatives and friends

The first database of information resources for cancer patients produced by the CRO⁴ constituted the "core" of the new project "Azalea", which was extended nationwide when the ACC (Alleanza Contro il Cancro, "Alliance Against Cancer"), a body set up by the Ministry of Health, officially recognised its national importance and supported it (2003). Coordinated by CRO of Aviano and the Regina Elena Institute of Rome, it is based on the collaboration of the seven oncological IRCCS (11 institutions at the moment).

Azalea's figures at present: 1600 records of reliable information material, mainly in Italian, nearly 400 full texts, about 1350 associations and non-profit organizations, mainly authors of the documents. Clinical trials open for participation and institution directories are

planned to be inserted. Nearly 200 records have been systematically validated according to a “well defined” methodology created in accordance with international criteria of quality evaluation of Internet content. More than 16,000 documents are viewed on the web site www.Azaleaweb.it every month. The key strengths of Azalea lie in: a team composed of multi-disciplinary professionals, international standards for cataloging and integrating information⁵, active involvement of patients and voluntary associations, and quality evaluation of material. The virtual aspect is supported by continuing interaction with the library system for all patients requiring tailored information support. We are now working on a new project (SICOP): its aim is to create a network, a System, among the “Points of Information and Communication in Oncology (PICO), along the lines of the “Aviano model”, created in different Italian institutions in cooperation with the voluntary associations and based on the informational support of Azalea and other sources. Thanks to this important synergy it is possible to guarantee the efficient diffusion of information related to health care and overcome the limitations of information online. The next aim for Azalea is the expansion into non-oncology sectors and non-IRCCS organizations: Azaleaplus - the information and communication system for patients and the general public.

1. Annunziata MA. Ethics of relationship. From communication to conversation. *Ann N Y Acad Sci.* 1997 Feb 20;809:400-10
2. Chamberlain Michael A. (1994): New technologies in Health Communication: Progress or Panacea? In Ratzan, 1994.271-284
3. Eysenbach, G. and Kohler, C. Does the Internet Harm Health? Some Evidence Exist That the Internet Does Harm. *BMJ* 2002;324(7331):238-9
4. I.Truccolo et al.: Living with cancer: An Italian Oncologic Data Bank of Literature for patients and common people: just to begin. 8th EAHIL CONFERENCE, Koeln Sept 2002
5. G. Cognetti, L. Cecere: E-Oncology and Health Portals: Instructions and Standards for the Evaluation, Production Organisation and Use. *Journal of Experimental & Clinical Cancer Research*, 22(4), 2003