

National Cancer Information Service in Italy: an information points network as a new model for providing information for cancer patients

Ivana Truccolo¹, Rosaria Bufalino², Maria Antonietta Annunziata³, Anita Caruso⁴, Anna Costantini⁵, Gaetana Cognetti⁶, Antonio Florita², Dina Pero⁷, Patrizia Pugliese⁸, Roberta Tancredi⁷, and Francesco De Lorenzo⁷

¹Biblioteca Scientifica e per i Pazienti, Centro di Riferimento Oncologico IRCCS, Aviano; ²Direzione Scientifica, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan; ³Struttura Operativa Semplice Dipartimentale di Psicologia Oncologica, Centro di Riferimento Oncologico IRCCS, Aviano; ⁴Struttura Formazione IFO, Istituti Fisioterapici Ospitalieri, Rome; ⁵Unità Operativa Dipartimentale di Psiconcologia, Azienda Ospedaliera Sant'Andrea, Rome; ⁶Biblioteca Digitale, Centro di Conoscenza "Riccardo Maceratini", IRCCS Istituto Nazionale Tumori Regina Elena, Rome; ⁷Associazione Italiana Malati di Cancro, parenti e amici (AIMaC), Rome; ⁸Unità Operativa Semplice Dipartimentale Psicologia, Istituti Fisioterapici Ospitalieri, Rome, Italy

ABSTRACT

The international literature data report that good information and communication are fundamental components of a therapeutic process. They contribute to improve the patient-health care professional relationship, to facilitate doctor-patient relationships, therapeutic compliance and adherence, and to the informed consent in innovative clinical trials.

We report the results of a multicentric national initiative that developed a 17-information-structure network: 16 Information Points located in the major state-funded certified cancer centers and general hospitals across Italy and a national Help-line at the nonprofit organization AIMaC (the Italian oncologic patients, families and friends association), and updated the already existing services with the aim to create the National Cancer Information Service (SION). The project is the result of a series of pilot and research projects funded by the Italian Ministry of Health.

The Information Service model proposed is based on some fundamental elements: 1) human interaction with experienced operators, adequately trained in communication and information, complemented with 2) virtual interaction (Help line, Internet, blog, forum and social network); 3) informative material adequate for both scientific accuracy and communicative style; 4) adequate locations for appropriate positioning and privacy (adequate visibility); 5) appropriate advertising.

First results coming from these initiatives contributed to introduce issues related to "Communication and Information to patients" as a "Public Health Instrument" to the National Cancer Plan approved by the Ministry of Health for the years 2010-2012.

Key words: cancer, communication, information services, patient empowerment, psychological support, quality of life, inequalities, rehabilitation.

Contributors: Associazione Italiana Malati di Cancro, parenti e amici (AIMaC), Roma; Azienda Ospedaliera Sant'Andrea, Roma; Azienda Ospedaliero-Universitaria "Ospedali Riuniti" di Trieste; Azienda Ospedaliero-Universitaria San Giovanni Battista di Torino; Centro di Riferimento Oncologico IRCCS, Aviano; Fondazione IRCCS Istituto Nazionale dei Tumori, Milano; Fondazione Salvatore Maugeri - Clinica del Lavoro e della Riabilitazione IRCCS, Pavia (due Punti Informativi); Fondazione San Raffaele del Monte Tabor, Milano; IRCCS Istituto Nazionale per la Ricerca sul Cancro, Genova; IRCCS Istituto Nazionale Tumori Regina Elena, Roma; Ospedale Casa Sollievo della Sofferenza IRCCS, San Giovanni Rotondo; Istituto Nazionale Tumori IRCCS Fondazione Pascale, Napoli; Istituto Tumori "Giovanni Paolo II" IRCCS Ospedale Oncologico di Bari; Ospedale San Giovanni Calibita Fatebenefratelli, Roma; Seconda Università degli Studi di Napoli; Università degli Studi di Napoli Federico II, Italy.

Acknowledgments: We thank Claudia di Loreto and Anna Vallerugo. The study was supported by the Alliance Against Cancer Network.

Correspondence to: Rosaria Bufalino, Scientific Directorate, Fondazione IRCCS Istituto Nazionale dei Tumori, Via G Venezian 1, 20133 Milan, Italy. Tel +39-02-23902107; fax +39-02-23903141; e-mail rosaria.bufalino@istitutotumori.mi.it

Received December 31, 2010; accepted May 11, 2011.