ABOUT US

Our history began in the mid 90s, when the Italian media launched a particularly intense, emotional campaign promoting an alternative cancer treatment developed by Dr. Luigi Di Bella. For a few months, the media reported on "miraculously cured" patients, although Di Bella never published any detailed results, causing a heated national debate arousing enormous uncertainty in cancer patients, many of whom turned to this "new non-toxic method" after conventional chemotherapy had failed. In the "Di Bella era", we as health care professionals experienced first hand the existing gap between what patients needed and what was actually offered to them, and the inability to adequately inform and communicate with patients and their relatives emerged as a particularly strong and urgent issue. We then decided to launch a series of investigations aimed to learn patient opinions and needs, understand the Italian context and identify possible answers to such needs. For this purpose we set up the GICO (Italian Group for the Study of Information and Communication in Oncology) and carried out two investigations which involved 2.600 patients and 13 hospitals.

- Passalacqua R, Campione F, Caminiti C, Salvagni S, Barilli A, Bella M, Barni S, Barsanti G, Caffo O, Carlini P, Cinquemani G, Di Costanzo F, Giustini L, Labianca R, Mazzei A, Olmeo N, Paccagnella A, Toscano L, Cocconi G.

Patients' opinions, feelings, and attitudes after a campaign to promote the Di Bella therapy. Lancet. 1999 Apr 17;353(9161):1310-4. Erratum in: Lancet 1999 Jun 12;353(9169):2078.

- Passalacqua R, Caminiti C, Salvagni S, Barni S, Beretta GD, Carlini P, Contu A, Di Costanzo F, Toscano L, Campione F.

Effects of media information on cancer patients' opinions, feelings, decision-making process and physician-patient communication.

Cancer. 2004 Mar 1;100(5):1077-84.

In 2004, a randomized, controlled trial funded by the Italian Ministry of Health was conducted, testing the effectiveness of a new modality of providing adequate information according to patient needs in oncology wards. This organizational model called for the creation of dedicated spaces, availability of selected information material, and the presence of staff specifically trained to provide information, devoting the necessary time to such activities. The Facility devised and tested in the project, termed PIS (Point of Information and Support), is not merely a library containing informative material for people with cancer, rather it is a place devoted to informing, where discretion and privacy are ensured. The PIS is managed by qualified nursing staff, who attended training specifically designed for the project aimed to acquire the necessary skills for this task. The crucial role nurses play in patient information/education has been suggested by numerous international studies since the 1990s, however in Italy, only after the introduction of the PIS have oncology nurses taken up the responsibility of informing patients following a "structured" model.

- Passalacqua R, Caminiti C, Campione F, Diodati F, Todeschini R, Bisagni G, Labianca R, Dalla Chiesa M, Bracci R, Aragona M, Artioli F, Cavanna L, Masina A, De Falco F, Marzocchini B, Iacono C, Contu A, Di Costanzo F, Bertetto O, Annunziata MA

Prospective, multicenter, randomized trial of a new organizational modality for providing information and support to cancer patients.

J Clin Oncol. 2009 Apr 10;27(11):1794-9. Epub 2009 Mar 9.

In the light of these encouraging results, a Task Force was set up under the aegis of AIOM (Italian Association of Medical Oncology), which enabled us to sensitize and involve in these issues many Italian oncology centers, and to extend the scope of our activities beyond research and study, to include clinical and care practice as well as all aspects of psychosocial care which, according to the literature, can help improve the health of patients and their caregivers, relatives and friends.

It should be noted that psychosocial care defines any treatments that patients need, other than active and supportive oncological therapies . They are provided by various health care professionals and involve different disciplines and fields of application, including psychological distress, social needs of various kinds, quality of life, pain control, etc.

This "Task Force" inspired the idea behind the HuCare (Humanization of cancer care) project, whose primary objective is to implement in oncological wards evidence-based interventions aiming to ensure psychosocial care to patients. 29 Italian cancer centers have participated in the project, directly involving over 700 health care professionals.

The HuCare project has produced several outputs. What follows is a brief description of the most important ones:

- development of the Italian version of a Question Prompt List (QPL) for patients, by carrying out transcultural adaptation of the tool compiled and validated at the University of Sydney, Australia. A QPL is a list of possible questions that can be put to the oncologist, given to patients before the consultation, which proved useful for encouraging communication between patients and physicians . Thanks to the HuCare project, now Italian-speaking cancer patients, living in Italy and abroad, may also benefit from this instrument.

- Production of a video for the dissemination of the experience of the project's participating centers, told in the first person by the figures directly involved (medical oncologist, nurse, psychologist, patient). The video is a useful tool for introducing the experience to centers intending to improve humanization of care by enacting the interventions of HuCare. Furthermore, because of its clarity and simplicity, the video may also be employed by participating centers to inform patients and their families about the information-education and support pathway offered at the ward.

- Publication, by the Italian scientific publishing company "Il Pensiero Scientifico", of a brochure featuring a guide to the implementation of measures called for by HuCare. Thanks to the wide readership of the publishing company, and to the brochure's posting on Facebook, the initiative will enable to spread awareness to a wide audience, health care operators and citizens alike, on the importance of psychosocial aspects connected with cancer, and on the positive impact of interventions specifically designed to improve them.

- Caminiti C, Diodati F, Filiberti S, Marcomini B, Annunziata MA, Ollari M, Passalacqua R.

<u>Cross-cultural adaptation and patients' judgments of a question prompt list for Italian-speaking</u> <u>cancer patients.</u>

BMC Health Serv Res. 2010 Jan 15;10:16. PubMed PMID: 20078873

- Passalacqua Rodolfo e Caterina Caminiti Come renedere più umana l'assistenza oncologica <u>Il Pensiero Scientifico Editore</u> (in stampa)