



Scientific Report 2005 UNIT OF PSYCHOLOGY

Marcello Tamburini, PhD, Psychologist, *Head*
Silvia Bettega, Social Worker, *Permanent Staff Member*
Claudia Borreani, PhD, Psychologist, *Permanent Staff Member*
Marco Bosisio, PhD, Psychologist, *Postdoctoral Fellow*
Cinzia Brunelli, ScD, Statistician, *Postdoctoral Fellow*
Simona Donegani, Psychologist, *Consultant*
Laura Gangeri, PhD, Psycho-Pedagogist, *Consultant*
Margherita Greco, PhD, Psychologist, *Consultant*
Micaela Lina, Psychologist, *Postdoctoral Fellow*
Luciana Murru, PhD, Psychologist, *Consultant*
Patrizia Trimigno, PhD, Psychologist, *Consultant*

The Unit of Psychology (www.QLMed.org/Psico/) is involved in the following Psycho-oncology fields: clinical, educational and research. Its activities are addressed to patients and their relatives, to health people at risk of cancer and to caregivers. These activities are carried out in co-operation with a large number of Units of the Institute.

CLINICAL ACTIVITY

Psychological reactions to disease and therapies are determined by the interaction of various factors and, in particular, by their impact on the personality and the defence mechanisms of the patient. Uncertainty and fear of the diagnosis, the hospital environment and waiting for the treatment procedure constitute a constant source of stress. Moreover, the effects of surgery in terms of permanent somatic changes and the subsequent treatment, with the possible feelings of failure of previous treatment, can make the patients particularly susceptible to psychological problems, sometimes of considerable gravity.

The activity of Clinical Psychology includes: individual psychological counselling; short psychotherapies; conversation and psycho-motor groups; psycho-educational groups; family therapies; psychological assessment. The psycho-oncologist, in the majority of cases, carries out his clinical activity in collaboration with the clinical and nurse staff of the Units of Surgery, Radiotherapy, Medical Oncology, Rehabilitation and Palliative Care.

A multidisciplinary clinical project, realised in collaboration with the Transplantation Unit, have been activated and specifically addressed to patients undergoing liver transplant for oncology illness. For patients with liver cancer, the transplant is often the only therapeutic possibility to guarantee survival and a high quality of life as well. Differently to the traditional surgeries, where the "ill part" may be removed, the transplant implies the substitution of the ill organ with the one explanted from an individual not living anymore. The transplantation represents an experience rich of complex psychological implications. This is a process where the personal psychophysical resources and external support (such as family) are very important and necessary. The complexity of this therapeutic process underlines the need use a multidisciplinary approach which considers both medical, psychological and social conditions of the patients.

Within the project "For a shared feeling: the man and the prostate cancer" (the psychological part of the prostate cancer program of Milan National Cancer Institute) Clinical Decision Making Counselling for prostate cancer patients was offered. During 2005 90 multidisciplinary (surgeon, radiotherapist and psychologist) first visits have been conducted. Thirty patients asked to continue with an individual psychological support to decide about treatment or to cope with the disease in a more functional and positive way or to face the sexual problems caused from the therapies.

Numerous psycho-educational groups have been conducted: a) The Ulysses program involved patients and their relatives in an educational program of information and psychological support; b) Stress management training and relaxation imagery; c) Touch therapy; d) Coping with fatigue and sexual difficulties in cancer.

During the 2005 302 patients (70% women) have been assisted. In total 1600 clinical consultations (1000 individual and 600 group) have been carried out.

With the aim to improve the communication with cancer patients and their family members, educational interventions for healthcare professionals are ongoing. The educational activity is addressed to: physicians, nurses, psychologists, voluntary assistants (this last one in collaboration with the Italian League Against Cancer). A project of individual training for physicians has been activated, as well as the participation of psycho-oncologists into the daily activity of groups working in the fields of pain therapy and palliative care, liver transplantation, hereditary tumours, rare tumours. "Paradigma", the School for psychological education in oncology, resides within the Unit. During this year the following courses have been activated: first-level course in psycho-oncology,

superior course for psychologists in psycho-oncology for palliative care, and some monothematic courses for clinicians and psychologists. Lastly, one course addressed to heads of Associations of Volunteers has been organised in collaboration with the Italian League Against Cancer with the aim of giving the instruments for selection, training and organisation of volunteers.

Social Service

The main activities of the Social Service are:

- to collaborate in the search of rehabilitation or residential structures for patient that are not able to return home, or that need to continue their therapies elsewhere
- to collaborate in the search of an Hospice for terminal patients or in the organisation of the home care assistance
- to activate the municipal or ASL services providing nursing or social assistance .
- to facilitate the search of accommodation for in-patient's family.
- to inform patients regarding the civil invalidity pension granted by ASL and the working inability pensions granted by the INPS.
- to explain the formalities to comply with the regional reimbursements for trip and stay.
- to inform on the criteria to benefit from the Law 104/92.
- to facilitate the access for care of the foreign citizens not belonging to the European Community.

During 2005, 167 patients or their relatives have been assisted. The principal information given concerned the civil invalidity, the pensions granted by INPS and the search for accommodation.

RESEARCH ACTIVITY

The research activity of the Unit has been mainly orientated towards the evaluation of the subjective impact of cancer and the treatments on patient's quality of life, on psycho-social aspects related to the different phases of cancer, and on hospitalised patients' needs.

Since 1998 the Psychology Unit has been developing a new research area through the application of qualitative methods. Narrative analysis has been applied to cancer patients' interviews regarding their illness experience. Deep interview method has been employed to focus on the main dimensions of *good and bad death* among general population. Focus Groups with nurses were conducted to highlight the main topics regarding the caring of patients dying in the hospital.

In 2005 a study aimed at developing a structured interview for the evaluation of end of life preferences in terminal patients was started. The development process of the questionnaire will follow five distinct phases: Phase I: Literature search aimed at identifying relevant issues. Phase II: Item generation; Phase III: expert examination of the first preliminary version; Phase IV: Pre-testing of feasibility, comprehensibility and acceptability of this first version on a sample of 15 terminal patients and modifications needed. Phase V: psychometric testing of the questionnaire obtained from phase IV. During 2005 phases from I to III were completed and a first version of ELPI (End of Life Preferences Interview) is now being tested on a sample of patients.

In the course of 2005 the steps needed to activate four different studies on a new system called "Wireless Health Outcomes Monitoring System" (WHOMS) have been completed and the studies are ready to start in the first months of 2006. The WHOMS, which has also received "Premio Sanità Forum P.A. 2005, is aimed at helping to detect patient suffering at a distance and was developed in collaboration with Reply and tested on a sample of cancer patients. The system allows physicians to send short questionnaires to patients' mobile phone handsets, then patients can answer on their

phone and return the completed form to the physicians using their GPRS connection (General Packet Radio Service). The forms are automatically collated and presented to physicians on a secure web page; the graphic display of the patients' information gives the medical staff a quick overview of how patients' symptoms are evolving. If any patient has seriously modified symptoms, a flashing light will appear by their name. This should help doctors to prioritise those in serious need. WHOMS can thus reduce the necessity to use printed questionnaires in monitoring the health and quality of life of patients, which should make the doctor-patient communication easier.

A demonstration of how the survey method works is available at www.gimed.org/whoms.

The first of the four studies planned on WHOMS will be focused on elderly patients with breast or prostate cancer treated with radiotherapy; the second study on patients who have undergone bone marrow transplantation; the third will be conducted on patients who have undergone surgery for melanoma or sarcoma; the fourth on patients with cancer pain treated by patients controlled analgesia devices. All the four studies have the common aim to document if, when and how much the continuous monitoring of the health status has lead to an early identification of the patients problems activating a well-timed intervention.

Health and Quality of Life Outcomes is an Open Access, peer-reviewed, online journal offering high quality articles, rapid publication and wide diffusion in the public domain. The journal is included in MEDLINE, and all articles are listed in PubMed and PubMed Central (PMC). Health and Quality of Life Outcomes aims at promoting the dissemination of knowledge on the Health-Related Quality of Life (HRQOL) assessment within the scientific community (www.qimed.org/HQLO/). The Journal, encompasses all aspects of the evaluation of medical therapies or psychosocial approaches, and studies on psychometric properties of Health-Related Quality of Life (HRQOL) measures, including cultural validation of instruments. The Editorial Office of the journal is located at the Unit of Psychology, Marcello Tamburini is the Editor-in-Chief and about 60 international experts collaborate in the Editorial Board. During 2005 83 papers (74 Research articles and 9 Reviews) have been published by the Journal.