Beyond biology

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This issue of *Journal of Medicine and the Person* includes two of three papers [1–3] based on lectures given in an Italian National Congress named “Global approach to the cancer patient”, held in Forlì from 25 to 27 November 2009. The three lectures made up the inaugural session on *Beyond Biology*.

A reductive *ethical* vision of medicine brings the risk of keeping separate a *humanistic* viewpoint from a *technical-professional* approach, each with its own rules and regulations. The *humanistic* approach is usually adopted just as a theoretical inspiration *at the beginning* of clinical activity, and then recovered *at the end* of the care-relationship (also from a chronological point of view, i.e., at the end of life).

Putting these reflections in the program of an oncology conference stems from the awareness that the object of medical care is an individual, a unique entity. “Doctors do not deal with ... complex animals ... They dedicate themselves to beings who are trying to make sense of their own suffering, to find a connection between life and the destiny that they feel is theirs. Illness arouses a strong impulse toward such an understanding, and the doctor-patient bond is a relevant contribution that in such a task the patient will not feel alone” [4]. The above-mentioned fragmentary approach is simply not appropriate. The oncologist Gianni Bonadonna said: “We must constantly question this fragmentary vision of medicine, which depicts the patient as merely some sort of dysfunctional

machine. As a patient I had first-hand experience of this. It was difficult, because I wasn’t any old observer. I was a patient who wanted to recover” [5].

A realistic method of knowledge and understanding of the object of healthcare must take into account both the human and professional needs of patients and their relatives, and this is therefore the only possible strategy to use. The appropriateness of such an approach results in a corresponding satisfaction felt by the person who is cared for. This satisfaction is expressed in terms of “experiences”, and in most cases it is hard to measure using quantitative approaches. Two examples of this come to mind. Father Aldo Trento, director of the non-profit Hospice “Casa Divina Providencia San Riccardo Pampuri”, set up on May 2004 in Asuncion, Paraguay, one day asked a patient how he was feeling. Although the patient was dealing with numerous unresolved health problems and had had little sleep during the night before, he replied, to the great surprise of Father Aldo: ‘Very well, Father’. Another personal case: the husband of a patient who died in our Hospice wrote to us a few weeks after his wife’s death: ‘I received your questionnaire on how satisfied relatives are with the service provided’... “and will be more than happy to fill it in. The only problem is that the questionnaire doesn’t give me the opportunity to express my feelings, and so I’ve decided to write you a letter as well, which I attach to the questionnaire” [6].

In this Journal issue Bregni’s article presents a critical review of the concept of quality of life and on the ways of evaluating it [1]. The numerous papers cited bear witness to the fact that the “truest” quality of life is represented by the pattern of important relationships woven into the tapestry of human life. Quality of life is a relational concept that depends on communication between patient and doctor, between a patient and his or her

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support network of family and relatives, and between the entire family and the medical team of caregivers. These relational qualities must be taken into account along with the elements that are normally used to determine quality of life [7]. In an article published in *Quality of Life Research* in 2007 [8], Steel compared quality of life questionnaires completed by advanced hepatocarcinoma patients with those of patients visiting their GPs for minor ailments. Quality of life values of the cancer patients were all lower than those of their “minor ailment” counterparts, with the exception of the value pertaining to well being, especially social and family well being, as though a solid network of support from family and friends is activated around the cancer patients. This has also been confirmed by other authors in their investigation of the SMiLE (Schedule for Meaning in Life Evaluation) questionnaire. Patients most often indicated areas related to relationships as providing *meaning in life* (MiL). MiL of cancer patients was surprisingly high, possibly due to the “response shift” of the severely ill. Further studies were considered necessary by the authors to improve our understanding of this characteristically human concept, which is “so easy to perceive, and so difficult to grasp” [9].

Clinical psychology studies have recently identified and described a method for dealing with difficulties, which helps the person involved to mature. It is referred to as “post-traumatic growth” or, looking at it from another angle, as “resilience”, and has also been identified as being closely related to the quality and typology of social support received by the person [10]. The quality of relationships is known to have an important impact on the extent of the request for euthanasia, which is virtually non-existent in well-run palliative care units [11]. In that sense, instruments for the psychological evaluation of “distress”, as reported in this journal issue by Grassi et al. [2], can help to identify cancer patients and their relatives in whom anxiety or reactive depression triggered by the disease actually brings about an emotional paralysis of the ‘self’, making the patient lose his or her sense of self-awareness and of his or her own existence, and thus making it more difficult to cope with the disease [12].

A scientifically correct evaluation of results obtainable from antitumoral treatments can help the clinician to decide when a therapeutic proposal risks becoming “futile, burdensome, excessive”. If this is not done, what is considered acceptable therapeutic persistence can rapidly become overtreatment, with no possibility of attaining the results aimed for, which results in an unjustified burden on the patient. In the next issue, Nanni [3], will

report the third contribution. A correct analysis requires an assessment of a number of issues: survival prognostic factors, wishes and expectations of the patient, and qualitative-quantitative results expected from standard reference therapies and from innovative experimental approaches [13, 14]. An excessive and inappropriate use of diagnostic-therapeutic approaches can be demonstrated *a posteriori* using indicators of the quality of care, e.g., extent of the use of chemotherapy (even in chemoresistant tumours) in the last days of life, and the use of experimental drugs with no evidence of efficacy in clinical practice [15].

References

1. Bregni M (2010) Quality of life and meaning of life: measuring the unmeasurable. *J Med Pers*, 8:60–64
2. Grassi L (2010) Emotional distress in cancer: clinical and educational implications. *J Med Pers*, 8:51–59
3. Nanni O (2010) The limit of therapy in oncology. *J Med Pers*, in press
4. Cesana G (2005) Il “Ministero” della salute. Società Editrice Fiorentina (SEF), Florence
5. Bonadonna G (2008) Quality of life from the point of view of the patient-physician. *J Med Pers* 6:65–66
6. Maltoni M (2009) In hospice la vita non si misura dalla “qualità”. *Avvenire*, 17 December
7. Ellis C (2008) Beyond measure: the role of stories, conversations, and personal narratives in Quality of Life research. *J Med Pers* 6:104–112
8. Steel JL, Chopra K, Olek MC, Carr BI (2007) Health-related quality of life: hepatocellular carcinoma, chronic liver disease, and the general population. *Qual Life Res* 16:203–215
9. Stiefel F, Krenz S, Zdrojewski C et al (2008) Meaning in life assessed with the “Schedule for Meaning in Life Evaluation” (SMiLE): a comparison between a cancer patient and student sample. *Support Care Cancer* 16:1151–1155
10. Barskova T, Oesterreich R (2009) Post-traumatic growth in people living with a serious medical condition and its relations to physical and mental health: a systematic review. *Disabil Rehabil* 3:1–25
11. Comby MC, Filbet M (2005) The demand for euthanasia in palliative care units: a prospective study in seven units of the “Rhône-Alpes” region. *Palliat Med* 19:587–593
12. Grassi L, Sabato S, Rossi E et al (2009) Affective syndromes and their screening in cancer patients with early and stable disease: Italian ICD-10 data and performance of the Distress Thermometer from the Southern European Psycho-Oncology Study (SEPOS). *J Affect Disord* 114:193–199
13. Tassinari D, Montanari L, Maltoni M et al (2008) The palliative prognostic score and survival in patients with advanced solid tumors receiving chemotherapy. *Support Care Cancer* 16:359–370
14. Harrington SE, Smith TJ (2008) The role of chemotherapy at the End-of-Life: “When is enough, enough?” *JAMA* 299: 2667–2678
15. Earle CC, Landrum MB, Souza JM et al (2008) Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol* 26:3860–3866