

**PRESIDENTIAL SYMPOSIUM. INTERNATIONAL PSYCHO-ONCOLOGY  
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**THE PROTECTION AND PROMOTION OF HUMAN RIGHTS AND DIGNITY  
FOR CANCER PATIENTS – AN IPOS RESPONSIBILITY**

Thanks – Dr Bill Breitbart for this forward initiative, distinguished panel colleagues (Drs Grassi, Travado, Baider and Brennan), and our sponsor, the Open Society Institute. I can think of no more appropriate body to sponsor this symposium, with its encouraging aims and aspirations. Like many, I have come away from lectures by George Soros, much the better from the experience.

Last August at the UICC World Cancer Congress, Mary Robinson, the first female President of Ireland and former United Nations High Commissioner for Human Rights, delivered a report relating cancer issues to human rights. Recently Robinson said something which is central to our own mandate - "I have always viewed healthcare as a fundamental issue of human rights. It is estimated that about one-third of cancers can be cured if detected and treated early. It is up to all of us -- governments, non-governmental organizations, cancer survivors, all concerned individuals -- to see that detection and treatment are offered to as much of the world's population as possible."

Our IPOS, with a diverse membership of physicians, social workers, nurses, psychologists, psychiatrists, spiritual care specialists, epidemiologists, social scientists, and educators, can be an essential player. Our stated aim is that all cancer patients and their families throughout the world receive optimal psychosocial care at all stages of disease and survivorship. IPOS is also the preeminent international resource for the dissemination of information and development of interventions that reduce cancers related to lifestyle, behaviors, and optimize care. As the cancer and health fields move toward greater protection and promotion of human rights and dignity as an international norm, it is incumbent on us, individually and as a professional dedicated cancer association, to take our place as both providers of and advocates for these standards.

If "human dignity" is the cornerstone of rights, we need to better protect and promote the dignity of patients and families in all aspects of cancer support, treatment and planning. As we note an acceleration in the global initiative to look at cancer care, palliation and pain control through the prism of human rights, several questions emerge. For example, what are the human rights obligations of the various players - researchers, civil society, pharmaceuticals, governments, international bodies, non-government organizations, cancer organizations and the United Nations? How does thinking of

cancer treatment as a human rights issue impact on public health services? How can the good initiatives of leaders such as Mary Robinson be mobilized at the popular level?

With the limited time at our disposal today, let me refer to several points, ending with one or two recommendations which could become our professional responsibility.

### **Human Dignity – the cornerstone of human rights, values and responsibilities.**

The “revolution of human dignity” (Janos Toth) continues. There isn’t another profession which respects the notion of human dignity as much as ours. It is a hall-mark of practice. In our midst, we have colleagues such as Harvey Chochinov whose Dignity Model addresses the psychosocial aspects of care and offers specific interventions to preserve dignity, especially in palliation. (see Thompson and Chocinov, Current Opinion in Supportive and Palliative Care 2008: 249-53) Dignity therapy provides clinicians with guidance and direction on how they may approach dignity concerns. Moreover, it is one more reminder that dignity for the patient is our trump card (or should be). Put this way, every treatment and modality offered to the cancer patient from diagnosis to death, should be delivered with respect for the inherent dignity of each patient... that is their right, it is our responsibility.

The notion of human dignity has a broad acceptability through usage and grounding in the Universal Declaration of Human Rights, although there is room for philosophical and cultural debate as to its precise meaning. [The opening phrase of the Universal Declaration recognizes the inherent dignity of all members of the human family.] The Declaration has achieved the status of international law. Great respect has been shown for the concept of human dignity from all corners. There are philosophical distinctions and cultural nuances. However, in relation to human rights, philosophers of law assure us that questions of dignity are rooted outside of jurisprudence. It is ‘pre-legal’, as it were. So, for us, it means that it is a “given”, and it is the base from which all our practice proceeds. The base will allow us to formulate our goals in terms of human rights.

### **Human Rights.**

Exactly ten years ago to the day (June 25, 1999) the Parliamentary Assembly of the Council of Europe adopted a document on the protection of the human rights and dignity of the terminally ill and the dying. Its opening sentence says that “The vocation of the Council of Europe is to protect the dignity of all human beings and the rights which stem therefrom” ... and in sec.5 states: “The obligation to respect and protect the dignity of a terminally ill or dying person derives from the inviolability of human dignity in all stages of life.” [Recommendation 1418 (1999)]. At the global level, much has been

argued and written about the link between human rights and health. These links continue to be made.

Health as a fundamental human right is found in many international instruments. The International Covenant on Economic, Social, and Cultural Rights makes the obligation clear for States Parties to the Convention. Article 12.1. recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health... and in 2d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness.

These rights are examined and receive comment at the ECOSOC committee level, which stresses certain core obligations of signatory nations: to pursue goals of access to health facilities; to provide essential drugs; and to pursue a national public health strategy. The right to health is considered a right of 'progressive realization' under international law. All nations are expected to take positive steps towards increased services.

### **Palliative care and pain control framed as human rights.**

To die with dignity is a notion to which we ascribe, professionally and personally. The palliative journey for cancer patients needn't be a physically painful one for most. Yet, according to the WHO, approximately 80% of the world population has either no or insufficient access to treatment for moderate to severe pain. Every year about 4 to 5 million cancer patients, at the end of their lives, suffer from such pain without treatment: "Most, if not all, pain due to cancer could be relieved if we implemented existing knowledge and treatments... There is a treatment gap: it is the difference between what can be done, and what is done about cancer pain." [World Health Organization, *Achieving Balance in Opioid Control Policy*, p.1].

The international palliative hospice care community has made significant inroads in relation to palliative care and human rights. There is no need for me to cover this ground, championed and led so well by our Symposium colleague, Dr Frank Brennan. [see also Frank Brennan, "Palliative Care as an International Human Right," *J Pain Symptom Management* 2007;33:494-499]. The process is furthered in various fora and publications. A recent international summary comes from Human Rights Watch, with its publication of March 2, 2009 – "Please, Do not make us suffer any more..." This 40 page report contains several recommendations to governments around the world; to global drug policy makers; to WHO, UNAIDS, and the donor community; to the global human rights community.

## **Psychosocial (and existential) pain.**

Almost all the discussion to date has pertained to physical pain, and more precisely, to the use of opioids ... their underuse, training for use, national narcotics controls (illicit trafficking on the one hand and adequate availability for medical/scientific purposes on the other) and urban myths surrounding narcotics. What WE know is that pain beyond the physical is just as ruthless. In the labyrinth of the cancer journey, there is psychosocial, emotional and spiritual pain. We also know that physical symptom management influences this type of pain. As a survivor, I remember clearly the emotional pain for me, and my family, after biopsy results. It was as severe as any of the pain and discomfort experienced in treatment and post-treatment, now seven years ago. Today we have a growing cadre of trained practitioners and a science which can meet the need of this debilitating pain. Additionally, in our front lines practice, many of us have seen pain symptoms over-treated with aggressive narcotics by well meaning physicians, when we knew that the existential pain might have been at its source.

Patients, and families, have the right to cancer treatment in all dimensions of the illness. This is a reality which we are more prepared to address due to increased training and research, clearer professional standards and better transferable education. It is suggested that 80% of cancer patients need extra care. We are also aware of the socio-economic dimension, as the psychosocial consequences of debilitating illnesses such as cancer are particularly grave for the poor.

We ask, can this treatment availability be left to the whim of cancer program managers or cancer hospitals? From last October's Canadian Palliative Care Memorial Service: "As we remember those with whom we have been so honored to journey, I never forget that the best of palliative care and pain control is not out of our kindness ... it is their human right based in human dignity." To state that modalities of treatment under the psychosocial banner is a human right, is pretty powerful language. Powerful, because we are at the stage of scientific development and professional competence where we can offer these skills. We are also in a position to become a training body for basics in caring ... through family members and civil society citizens in many nations. Not everywhere and in all places to be sure, but projecting the progress of even just the past decade, we are in a position to join with others in the actualization of health care and cancer care as a human right ... from cancer control to cancer distress and family counselling. The right to psychosocial care will remain appropriate and proportionate to circumstances, but this does not remove it from the category of a human right to be pursued.

## **Considerations for a New Initiative, through Partners and Links**

- 1) The international palliative care movement has already exercised research and practical initiatives in this field. Some of us here also sit on palliative care teams associated with our clinics, and know that psychosocial cancer support

and palliation is a seamless journey. The international palliative care model would serve as a sound base. This is a strong and proven resource.

- 2) Psychosocial oncology associations continue to grow in regions and countries. There is a sensitive and knowledgeable resource base available through the IPOS family.
- 3) A myriad of national cancer agencies is available for partnering and consultation.
- 4) This morning, we have a senior staff person from the UICC with us. There are many initiatives under the purview of the UICC. One is the World Cancer Declaration, which IPOS has signed. It can be framed also in human rights terms. Under its direction, the campaign to control cancer is active in many countries with exceptional public leadership and partners. [For example, I have been asked to give a workshop on Human Rights and Cancer Control at a Global Leadership Forum this coming autumn].
- 5) The World Health Organization is important for the impact of our work. It has taken the issue of the right to health to a level which should allow a collaboration ensuring the recognition of our own evidenced based practice in cancer care. Since psychosocial cancer care must be realized in widely divergent countries according to capacity, we can appreciate the WHO style of recommendation for different resource settings.
- 6) A liaison may be necessary with the United Nations Human Rights Commission and Regional and Domestic Human Rights Bodies. Back in the 1970s, when I first encountered the UN Commission on Human Rights and was involved in Resolution and Convention design ... the first phrase I often heard was "human rights' grinders". Changes do not take place overnight ... but require monitoring, commitment and preparation. Issues of compliance and enforceability are always concerns in the human rights field. It is my dream that the Special Rapporteur of the Human Rights Commission on the right to health, will one day be addressing the right of cancer patients to psychosocial cancer care. The reporting mechanism, already in use, will be a mechanism by which governments be reminded of their obligations in our field.
- 7) Moral suasion and public backing. Our experience will be that the protection and promotion of human rights and dignity for cancer patients will be viewed as a natural outcome of our work and vision ... and that the publics will carry the day for a new way of appreciating our contribution.

We have reached the stage where a human rights task force can be considered. The time is ripe for psychosocial oncology to be understood as a promoter of human dignity through human rights.

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