

The World Cancer Declaration: Promoting Equity, Human Dignity and Human Rights in Cancer Control

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[Relevant WCD targets: • 1. Ensure Effective Delivery Systems in all Countries • 2. Significantly Improve Measurement of Cancer Burden • 6. More Cancers Diagnosed via Screening & Early Detection • 7. Supportive Care * 8. Universal Availability of Effective Pain Control • 11. Major Improvements in Global Cancer Survival Rates]

The Protection and Promotion of Human Rights and Dignity in Cancer Control and Treatment

Introduction

As a Canadian, I am always honoured to speak in China. On the medical side, we are linked through Dr. Norman Bethune. He is best known as a hero in the People's Republic of China. But he also gained a reputation in his native Canada as a gifted surgeon, an inventor, a political activist and an early proponent of a universal health care system. Chairman Mao Zedong wrote a tribute titled "In Memory of Norman Bethune," in which he praised Bethune for his selflessness and dedication to the Chinese people. Most of my Chinese friends know that writing by memory.

At our last UICC World Cancer Congress in 2008, Mary Robinson delivered a report relating cancer issues to human rights. Robinson - "I have always viewed healthcare as a fundamental issue of human rights... 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." The Lance Armstrong Foundation added its voice - "Mary Robinson embodies the LIVESTRONG spirit of selfless service and leadership for the sake of positive change in our world. She has been a tireless advocate for issues at the intersection of health and human rights throughout her career -- and we share the view that cancer control is at its core an issue of human rights." – Lance Armstrong Foundation and CEO Doug Ulman, 2009.

Today, after a delay, we pick up on this powerful statement and re-affirm that cancer control and treatment is an international human dignity and human rights imperative. This imperative impacts directly on international, regional and national programs and goals. How to have international standards reflect the World Cancer Declaration is the challenge. Hope and change is the response – with a clear vision and time-line commitment.

The World Cancer Declaration and Beyond

The WCD is just that – a wonderful declaration. Dr. Eduardo Cazap will anchor it again today. As is the case with international "Declarations," can this translate into international obligations and responsibilities? Last month Dr Franco Cavalli, immediate past president of the UICC, wrote a short op-ed in the Cancer World Newsletter (July 5, 2010) - "Turning the World Cancer Declaration into Action." The WCD calls for urgent action to reach its 11 targets by 2020 in order to avoid a disastrous escalation in new cancers and to significantly improve cancer survival in all countries. While the Declaration has certainly elicited interest and considerable action, it is disappointing that "... efforts to use the Declaration as a template for developing regional or national targets have tailed off." Cavalli concludes that in light of the United Nations having recently recognized the urgent need for tackling non-communicable diseases like cancer, "... we now have a window of opportunity to regalvanise efforts where they are flagging, and prompt action where nothing has yet been done. The World Cancer Declaration will remain a vital roadmap to direct these efforts." Today, we pursue the role of human rights and dignity in this new window of opportunity.

Human Dignity

The cancer and health fields move toward greater protection and promotion of human rights and dignity as an international norm. What is our place, individually and as a professional dedicated cancer association, as providers of, and advocates for, these standards?

If "human dignity" is the cornerstone of human rights, who better than us to promote the dignity of patients and families in all aspects of cancer control, treatment and planning? "Human dignity" has a broad acceptability through usage and grounding in the Universal Declaration of Human Rights. The opening phrase of the Universal Declaration recognizes the inherent dignity of all members of the human family. The Declaration has the status of international law. Intellectual respect for the concept of human dignity has been shown from all corners. Since "dignity" is the flagship of all our endeavors, we can formulate cancer control goals in terms of human rights.

Health as a Human Right

Health as a fundamental human right is found in international instruments. Our colleague Jonathan Liberman will give us an up-to-date analysis. The International Covenant on Economic, Social, and Cultural Rights makes the obligation clear for all 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. The core obligations of signatory nations are: 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. The right to health has been enshrined in numerous international and regional human rights treaties as well as national constitutions all over the world. All nations are expected to take positive steps towards increased services. We continually ask: what commitments have governments made to ensuring the realization of the human right to health – the Earth Summit Rio, International Conference on Population and Development in Cairo, World Summit for Social Development in Copenhagen, Habitat II conference in Istanbul and so on.

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 heard was "human rights' grinders". Changes do not take place overnight ... they require monitoring, commitment and preparation. Issues of compliance and enforceability are always the concerns in human rights. To make a quantum leap forward, a current model (which could be paralleled for cancer) is the April 2010 report of the UNHCHR on preventable maternal mortality and morbidity and human rights (A/HRC/14/39). It is my dream that the Special Rapporteur of the Human Rights Council on the right to health, will one day before long be targeting cancer issues. The reporting mechanism, already in use, will be a mechanism by which governments are reminded of their cancer control and treatment obligations. And, as a result, non-government bodies, from cancer associations and organizations to the pharmaceutical industry, will note their responsibilities.

The journey has begun. Dr John Seffrin, writing in May 2008, in *The Lancet Oncology*. "Cancer Control as a Human Right": *Cancer is potentially the most preventable and treatable disease in existence, but without enhanced attention to public-health prevention campaigns, screening programmes, treatment centres, and palliative-care services, people in all countries, especially low-resource and middle-resource countries, will continue to be affected by and die needlessly from this disease Cancer is a worldwide problem, and disparities in cancer mortality are consistent with an unconscionable social inequality in access to public health and medical services. Worldwide cancer control is a human-rights issue and all world leaders and organisations have to work together to defend the human right of access to care.*

Let's not forget that the International Union Against Cancer (UICC) describes itself as the leading international non-governmental organisation dedicated exclusively to the global control of cancer. Its aim is a world where cancer is eliminated as a major life-threatening disease for future generations. The World Cancer Campaign is a response to the Charter of Paris adopted at the 2000 World Summit Against Cancer for the New Millennium. Article I from the Charter of Paris begins with the blunt statement: "Cancer patient rights are human rights." This calls for "an invincible alliance - between researchers, health-care professionals, patients, governments, industry and media - to fight cancer and its greatest allies, which are fear, ignorance and complacency".

When cancer control and treatment are viewed as human rights in terms of international obligations and responsibilities, the issue jumps to the forefront of international, domestic and regional agendas. Will the UICC step up to be the major player in this initiative? Can it sustain necessary strength, capacity and clarity of vision? With whom will it partner?

There is an acceleration in the global initiative to view cancer, as well as palliation and pain control, through the prism of equity, human dignity and human rights. Pain control and palliative care are well on the way to incorporate their issues as human rights mandates. The World Health Organization considers access to controlled medicines such as morphine a human right. It is virtually non-existent in over 150 countries. The WHO estimates that between 30 and 86 million people annually suffer from untreated moderate to severe pain. Now, strides are being made in effective pain control through the activities of the international narcotics control board, the UN NCC, and especially through the UICC's Global Access to Pain Relief Initiative (GAPRI) which aims to achieve Declaration Target 8: 'Effective pain control measures will be available universally to all cancer patients in pain'. This effective initiative is led by President David Hill and our panelist Jonathan Liberman is a member.

Our colleague Luzia Travado will outline the European situation in psycho-oncology. She also represents the International Psycho-Oncology Society as it formulates a Human Rights Declaration reflecting the WCD Target 7, supportive care, under the leadership of IPOS past president Bill Breitbart (note Dr. Breitbart's article "Palliative Care as a human right," *Palliative and Supportive Care* (2008),6, 323-325)

Several overall questions emerge. What are the human rights obligations or responsibilities of the various players - researchers, civil society, pharmaceutical industry, governments, international bodies, non-government organizations, cancer organizations and the United Nations? How does thinking of cancer as a human rights issue impact on public health services? What is the cultural impact from the perspective of a diversity of cultural history, on cancer control? What role can the medical community play in advocating cancer control as a fundamental human right? What are the bioethical issues involved in treating cancer programs as issues of dignity and rights? How do we have equity in a world with such economic disparities? What is the role of the United Nations, the UNHRC, WHO and other international bodies in viewing cancer as an issue of dignity and rights? Is there a championing role for other non-government agencies (such as Rotary International, as exemplified in their partnering in the abolition of polio) in working with the UICC and the UN? How can cancer control be translated as an OBLIGATION of nation-states and, let me dream, as a RESPONSIBILITY of the pharmaceutical industry (see Harvard School of Public Health, "Current Debates on Realizing Health and Human Rights: An annotated Bibliography on the Human Rights Roles and Responsibilities of the Pharmaceutical Industry"); and critically, **what concrete objectives and time-lines can we pursue?**

Engaging these questions could be the most important initiative in the cancer field in several years, moving outward from the base of the World Cancer Declaration.

World Health Organization

From the WHO constitution – "...the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being, without distinction..." Every country is now party to at least one human rights treaty that addresses health-related issues. The World Health Organization is and has been centrally important. 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. Cancer care/control can only be realized in widely divergent countries according to capacity. We appreciate the WHO style of recommendations for different resource settings - in human rights terms we speak of progressive rights. In addition to information and standard setting, can we expect the World Health Organization to have a more active advocacy role with its current structure? If not, why not ... and, with a need for increased advocacy, which international organs are best equipped?

Non-communicable Diseases (NCDs)

Cancers, along with cardiovascular disease, chronic respiratory disease and diabetes, among other non-communicable diseases, claim nearly 35 million lives every year. NCDs are the leading cause of death in the world. Continuing on the current trajectory, more than 40 million people will die from these NCDs annually by 2015. Many of the deaths caused by non-communicable diseases are in developing countries. In spite of signs that death rates from non-communicable diseases have stabilized or even declined in many high-income countries in recent decades, research points to deaths from these diseases increasing in all regions of the world. WHO's Assistant Director-General Ala Alwan puts it bluntly: "Tackling these diseases constitutes one of the major challenges for sustainable development in the 21st century." NCDs have been recognized on the agenda of the UN family just since May of this year. The most up-to-date cancer statistics (June 1, 2010 – GLOBOCAN 2008) would be from The International Agency for Research on Cancer, which provides the most accurate assessment of the global cancer burden and shows that in 2008 a majority of the 12.7 million new cases of cancer and the 7.6 million cancer deaths worldwide occurred in developing countries.

There is great anticipation of a high-level summit, with the participation of heads of State and Government, to take place as a UN General Assembly in New York in September 2011. I would hope that cancer control and treatment will be framed in human rights and dignity terms by that time ... and that a mechanism will be mounted to help avoid a continuation of the "words on paper syndrome."

Equity and Ethics

At this juncture, questions and answers are interwoven and complicated. Many of the deaths caused by non-communicable diseases in so-called developed and in developing countries, could be prevented by reducing exposure to tobacco use, unhealthy diets, physical inactivity and harmful use of alcohol, as well as improving early detection. As a governance issue, the unbridled negative manipulation of the environment is simply not challenged. We know that cancer and other non-communicable diseases are imposing a much greater burden on the poorest countries than on richer economies and must be tackled as a development issue. WHO Coordinator of Health Promotion Gauden Galea says that "...we are talking about countries and populations that are already dying at much higher rates and much earlier than people do in the richer economies." If we suggest that cancer and

the three other major chronic diseases are responsible for 60 per cent of the world's deaths, then 80 per cent of these deaths are happening in the poorest populations of the world.

The importance and value of human flourishing is paramount, regardless of culture or government. Reframing the discourse and thinking of cancer, to include a human rights and human dignity perspective, may assist in alleviating cultural and personal notions of 'shame' surrounding this disease. Far too many (millions) of cancer patients are not seen until stage IV. Likewise, when we add the human rights dimension, we likely lift another shadow ... a lack of transparency. As a professor, researcher, health care professional in a cancer treatment centre, and also a cancer survivor - I still think that there is far too little forthcoming information about research monies, citizen contributions, significant (not just statistically significant) chemical and pharmaceutical cost-benefits.

We know that most nations cannot afford equipment, personnel and funding to combat this growing scourge. As a right of 'progressive realization' under international law, countries are not expected to be equal in ability, but all are expected to do something according to means and priority. It distinguishes the inability from the unwillingness of a State Party to comply with its right to health obligations.

We can echo the words of Dr Simon Sutcliffe and others – cancer is one of the most preventable, treatable and curable of diseases. Through an additional focus on human dignity and rights, one would expect a deepening of cancer control advocacy from all corners, especially civil society and youth. Teenagers through to thirty year olds are the smartest, largest, most wired and selfless generation ever.

The equity part of cancer management has a strong social ethical dimension. Countries, so-called developed and developing, and financially emerging nations, are subject to both environmental and governance decisions, in addition to cultural and economic pressures. We are never removed from the Millennium Development Goals, each of which speaks to human health.

In the discourse out of Africa and Asia, there is occasionally a 'push-back' with regard to human rights language. Whatever the language, the field is one of ethics and behaviours. Qianfan Zhang, my colleague and fine legal scholar at Beijing's Peking University Law Faculty, reminds us that many nations fall short of an important ethical consideration. And China has a very strong tradition of ethics and dignity. In his paper written and tabled for today's symposium, "Human Dignity and Care for Cancer: A Brief Note from the Confucian Perspective," he writes, in part: "In the contemporary Chinese society, which has become increasingly mobile and less family oriented, the Confucian requirement is naturally extended, with the benefits of experience from the more developed countries, to the establishment of a socialized scheme that will allow effective treatment at an affordable cost. Such a scheme is woefully lacking in China, particularly in vast rural areas, where the vast majority of peasants are without meaningful medical coverage and, as a result, can only stay home to meet their destinies in pain once they are hit by major diseases. Even for ordinary city patients who are under some coverage and can marginally afford to pay for the treatment, they ordinarily incur high expenses; enough to put themselves and their families in jeopardy. It is ironic that, after more than two thousand years of development, China today is still far from the attainment of human dignity, an ideal envisioned by so ancient a thinker as Confucius or Mencius.

The Confucian teaching on human dignity is relevant to the topic of cancer in China and even the world today. It demands a way of life that is consistent with nature ("way of heaven", tiandao), by which an individual inculcates a sedate mind and healthy lifestyle, whether during ease or hardship, conforms his activities to the law of nature and requirements of living environment, and reduces the risk of cancers and other diseases to himself and others. It requires the officials to duly regulate air, water and food qualities, and to seriously implement these regulations for the protection of common people from potential food and environmental harms. And it imposes a positive duty on the government to establish an effective health care system, reaching out equally to the city residents and peasants, so that their dignity of life is not fatally undermined by cancers and like diseases."

Cancer can be controlled. Cancer could be eliminated. Cancer patients require early diagnosis, treatment and supportive care. The protection and promotion of human rights and dignity in cancer control and treatment can only be viewed as a natural outcome of our work and vision in the world community, as we help move cancer up the global health agenda. We are continually called to do as much as we can, wherever we can, and whenever we can. Can we envision a healthier world by 2020? Yes, we can together. Thank you.

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