Published in final edited form as:

Psychooncology. 2017 April ; 26(4): 563–569. doi:10.1002/pon.4209.

2015 President's Plenary International Psycho-oncology Society: psychosocial care as a human rights issue—challenges and opportunities

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Abstract

The International Psycho-Oncology Society (IPOS) Human Rights Task Force has been working since 2008 to raise awareness and support, for the relevance of psychosocial cancer care as a human rights issue. In 2014 the “Lisbon Declaration: Psychosocial Cancer Care as a Universal Human Right” was fully endorsed by IPOS. Subsequently, the IPOS Standard on Quality Cancer Care, endorsed by 75 cancer organizations worldwide, has been updated and now includes 3 core principles: Psychosocial cancer care should be recognised as a universal human right; Quality cancer care must integrate the psychosocial domain into routine care; Distress should be measured as the 6th vital sign. The President's plenary held at the 2015 World Congress of Psycho-Oncology in Washington DC was devoted to discussing psychosocial care as a human rights issue. Many challenges and opportunities are illustrated in different continents and contexts: from Africa where resources for basic cancer treatment are scarce and children and their parents face significant difficulties with hospital detention practices; to Europe where for many countries psychosocial care is still seen as a luxury; and the Middle East where Muslim women face stigma and a culture of silence over cancer. We further discuss how to move the Lisbon Declaration forward towards its

implementation into clinical practice globally, using the successful example of the World Health Assembly resolution supporting palliative care as a human right which has achieved widespread approval, and identifying the vital role the IPOS Federation of National Psychoncology Societies plays worldwide to move this agenda forward.

Keywords

psychosocial cancer care; human rights; standards of cancer care; psycho-oncology

1 Introduction

An essential element of high-quality comprehensive cancer treatment involves attending to the psychosocial needs of cancer patients and their families. In the last decade, we have witnessed great achievements in developing standards and clinical practice guidelines for the provision of psychosocial cancer care.^{1,2} We have seen recommendations for its inclusion into routine cancer care, implemented regular distress screening,^{3,4} and had psychosocial care included in important international cancer declarations and in main cancer policy documents.^{2,5} Despite these actions, psychosocial cancer care is still far from being offered regularly to all patients around the world. Significant differences in the provision of psychosocial cancer care across continents have been documented.^{1,6,7} North America, Europe, and Australia have more resources in this area and have greater availability of psychosocial services, although there is still a highly heterogeneous distribution among countries.^{1,6} Asia and Africa, on the other hand, have fewer resources for psychosocial care and, in some cases, have no services at all.^{1,7} This means that many cancer patients around the world still face psychosocial cancer-related needs that are neglected, thereby contributing to emotional suffering, suboptimal clinical outcomes, and diminished quality of life.

The International Psycho-oncology Society has long embraced advocating for psychosocial care as a human rights issue as part of its mission, and more specifically through its dedicated task force.

In 2015, the fourth President's Plenary at the 17th International Psycho-oncology World Congress in Washington DC was devoted to discussion and further awareness raising about this important topic and the successful work of the IPOS Human Rights Task Force. We present the Lisbon Declaration proposed by this task force, offering examples of the challenges and opportunities in different contexts across the globe, and how children in Africa and women in the Middle East are particularly affected. Moreover, we discuss how best to advance and support the declaration of psychosocial cancer care as a human right towards its implementation into clinical practice globally. We draw on the successful example of how a resolution supporting palliative care as a human right has achieved widespread approval, and the vital role of the IPOS Federation of National Psycho-oncology Societies worldwide to disseminate and implement this agenda forward.

2 The Lisbon Declaration: Psychosocial Cancer Care as a Human Rights Issue

The IPOS Human Rights Task Force¹ has worked, since 2008, to raise awareness and support, within IPOS and the Federated societies, to recognize psychosocial cancer care as a human rights issue to be advocated for internationally and nationally through existing human rights laws.^{8–10} Between 40% and 60% of cancer patients and family members experience psychosocial distress that requires intervention.^{11–13} Of the 30 million people worldwide with cancer, only a minority of those in need receive proper psychosocial cancer care by trained professionals, resulting in widespread suffering.

In November 2014 at the World Congress of Psycho-oncology in Lisbon, Portugal, the IPOS Board endorsed the “Lisbon Declaration: Psychosocial Cancer Care as a Human Right.”

This Joint Declaration and Statement of Commitment Calling for the Recognition of Psychosocial Cancer Care as a Human Right declares that we, as representatives of psychosocial oncology (PSO) and related alliances, federations, associations, organizations, interested parties, and stakeholders and as members of civil society hereby agree to work and collaborate together, worldwide to do the following:

1. identify, develop, and implement strategies for the recognition of psychosocial cancer care and treatment as fundamental human rights;
2. work with governments and policy makers to adopt the necessary changes in legislation to ensure appropriate psychosocial care of patients with cancer, cancer survivors, or those at risk of developing cancer;
3. advocate for improvements in access to and availability of psychosocial cancer care required for the effective treatment of the emotional, interpersonal, familial, and social impact of cancer;
4. promote screening for distress as the sixth vital sign, access to effective psychosocial interventions and essential medications, and training in communications and interpersonal skills for cancer care professionals;
5. advocate for adequate resources to be made available to support the implementation of psychosocial cancer care and PSO services where needed, including support of such services in cancer centers and ongoing professional training in psychosocial cancer care;
6. advocate for academic institutions, teaching hospitals, universities, and health care systems to adopt the necessary practices and changes needed to ensure that psychosocial cancer care, resources, personnel, infrastructures, review boards, and systems are created and sustained;

¹The IPOS Human Rights Task Force members are as follows: William Breitbart, MD, USA (Chair); Lea Baider, PhD, Israel; Stephen Connor, PhD, USA; Luigi Grassi, MD, Italy; David Morrison, Emeritus, Canada; Andrea Patenaude, PhD, USA; and Luzia Travado, PhD, Portugal.

7. encourage and enlist other international and national organizations, associations, federations, and interested parties to join this global campaign for the recognition of psychosocial cancer care as a human right; and
8. encourage the recognition that psychosocial cancer care must be provided in a manner consistent with the diversity of cultural, social, and religious contexts of individual regions and countries worldwide.

The IPOS Board then approved an update of the IPOS Statement on Standards and Clinical Practice Guidelines in Cancer Care endorsed by 75 cancer organizations worldwide to incorporate the *Lisbon Declaration*, which now includes 3 core principles:

- Psychosocial cancer care should be recognized as a universal human right.
- Quality cancer care must integrate the psychosocial domain into routine care.
- Distress should be measured as the sixth vital sign.

Moving forward, IPOS is seeking endorsement of its updated standard by the world cancer community, drawing on the power of human rights advocacy to raise the level of dignity in cancer care around the world.

3 The IPOS Federation's Perspective on Human Rights

By endorsing the IPOS Statement of Human Rights, it is mandatory that the IPOS Federation of National Psycho-oncology Societies direct its attention to all countries where psychosocial care is not provided to cancer patients, therefore denying their human right to receive proper intervention. The IPOS Federation currently consists of 29 psycho-oncology scientific societies in 28 countries worldwide, for a total of more than 7000 members. The 2012 and 2013 Federation reports underlined a mixed picture of psychosocial care around the world.^{7,14,15} Although most psycho-oncology societies, especially in Europe, North America, and the Asia Pacific area, have flourished, with some forms of structured liaison models with the national oncology and palliative care societies, there remains a general paucity of funding for education, research, and psychosocial cancer care. These data are particularly important given the several mandates of the Federation, including support of national societies in developing psycho-oncology where it does not yet exist.¹⁶

In 2014, the IPOS Federation conducted a further survey, asking each national society to rate the level of development of PSO practice in their own country, based as a rating criterion on the Global Atlas of Palliative Care at the End of Life.¹⁷ Responses were provided by 25 of 28 federated societies (response rate 89%), which indicated that standards regarding the provision of psychosocial programs are variable depending on the institution and the country. More specifically, psychosocial care was reported to be integrated into the mainstream of cancer care in disparate ways, specifically isolated care provision (24%), generalized care provision (20%), preliminary integration (40%), and advanced integration (16%) (see Table 1 for details).² Given that the IPOS Federated countries are expected to

²Responses in this survey were provided by each society (ie, by the president or a referent person) and represent their views and interpretations. The results of this survey are presented and discussed elsewhere (Grassi et al, submitted).

have relatively well-established PSO services, those where psycho-oncology societies do not exist are presumed to have worse situations. With respect to this, it has been reported that in many African countries, for example, availability of appropriate cancer intervention itself is a problem, with limited access to proper treatment. Regarding pain, the low availability of morphine because of import taxes, and many other barriers, often results in painful death.¹⁸ Kenya for example has less than 10 oncologists in the whole country with a population of over 40 million, and many cancer patients have to travel more than 600 km to reach a cancer center. Misplaced political priorities may create further problems, with funds dedicated to developing policies and guidelines, but without any apparent implementation and with insufficient resources for cancer treatment.¹⁹ Also, because of the economic crisis in many parts of the world (including Europe), a reduction of funds for psycho-oncology services has been noted, even in countries with PSO societies. Recognition of psychosocial care as a human right should help avoid the view that provision of such services is a luxury not belonging to the essential levels of care but it is mandatory.

For these reasons, the IPOS Federation has new, significant obligations added to its mission, specifically, (1) the analysis of psychosocial care as a human right for people with cancer in all the parts of the world, particularly, but not only, in developing countries; (2) the critical evaluation of existing psychosocial services and their organization to verify that the standards of care (and the human rights issues) are respected; and (3) the provision of ongoing, in-depth technical support to help in developing psycho-oncology societies as a possible facilitator of disseminating the message of universal psychosocial care for cancer patients and their families and implementing the creation of psychosocial clinical services.

4 Defining Psychosocial Care as a Human Right for Children with Cancer: An Example of Challenges at the Extremes

Approximately 160 000 children worldwide develop cancer annually.²⁰ Forty years of psychosocial research illustrates that children being treated for cancer require the presence of their parents to provide continuity and security, freedom from pain, clear communication about why they are being treated and when painful treatments will occur, and the ability to express themselves in language and through play.²¹ These should be inalienable rights of sick children.

The recognition that children have rights is a relatively new concept. In 1989, the United Nations Convention on the Rights of the Child was ratified by 194 countries.²² It provides that the child “needs special safeguards and care” (Preamble), that the “best interests of the child shall be a primary consideration” (Article 3), that the child “shall not be separated from his or her parents against their will” (Article 9) except when judicial review establishes that this is essential to their best interests, and that “No child shall be deprived of his or her liberty unlawfully or arbitrarily” (Article 37).

The rights of sick children are compromised when they are unnecessarily separated from their parents in ways that are not in their best interests. Hospital detention is defined as either refusing the release of living patients after medical discharge is clinically indicated or refusing the release of bodies of deceased patients to families until the hospital bill is paid or

waived.²³ These practices interfere markedly with advancement of medical care by reducing trust in the hospital system, discouraging parents from bringing children to medical attention immediately upon initiation of symptoms, and reducing adherence. Where hospital detention occurs, the number of children who get available, modern cancer treatment is markedly reduced, and the survival of those who do is significantly compromised because of late and/or incomplete treatment. Such practices discourage medical and other hospital staff striving to save lives under challenging conditions.

Several reports detail hospital detention practices occurring at Moi Hospital, Eldoret, Kenya, where children are detained when parents without health insurance or waiver³ are unable to fully pay the hospital bill.^{24–26} Half of the families endured detention of their children for periods ranging from 2 to 21 days.²⁴ Parents found this deeply distressing, often rendering them powerless, as they had few remaining resources after bringing the child for treatment.²⁵ There is a payment waiver system in Kenyan hospitals, but families are often not informed about it, the waiver criteria are not transparent, and even when successful, the waiver process takes 2 to 3 months, during which time charges accrue.²⁵

The Global Task Force on Hospital Detention of Children within Pediatric Oncology in Developing Countries Committee of the International Pediatric Oncology Society was formed in 2013 to bring an end to hospital detention and has 36 members from 14 countries. A recent position paper from the Task Force published in the *Lancet*²³ calls for government and nongovernmental human rights and professional organizations to work together to end hospital detention. The IPOS has endorsed the International Pediatric Oncology Society's efforts.²⁷

At the opposite end of the spectrum is a 3-year effort supported by the Mattie Miracle Foundation to define essential psychosocial care, which should be available to all children treated for cancer and their families. These standards were recently published in a special issue of *Pediatric, Blood, and Cancer*.²⁸ The challenge was to set standards that could be implemented in all developed pediatric oncology programs and help set goals for developing programs. Responsibility for ensuring provision of humane, appropriate psychosocial care of children with cancer begins with thoughtful observations of professionals working in this expanding area worldwide.

5 Delivering Psychosocial Cancer Care to Women Across the Globe: An Example of Challenges in the Middle East

The Middle East is among the highest in the world for population growth. The growth of 17 Middle East countries during 1990–2008 was 108.7 million persons—a 44% growth rate. The latest population statistics for Islamic religious affiliation is 93% for all the Muslim population in the Middle East.²⁹

³The waiver is a possible voiding of the bill, which can occur if a social service investigation finds the family to be of such low socioeconomic status that payment is unlikely; the waiver process, however, is guided by a committee, is often arbitrary, and has no defining rules to guide the process.

5.1 Psychological and sociocultural barriers to cancer care for Muslim women in the Middle East

Many factors limit access of Muslim women to psychosocial care when they have cancer: mistrust of cancer treatments, views that cancer is a punishment and always results in death, fear that cancer treatment will lead to sterility, and family stigma that results when a genetic family illness is viewed as causing dishonor.³⁰ The Organization of the Islamic Conference, an international Islamic organization founded in 1969, issued the Cairo Declaration on Human Rights within Islam in 1990. This Declaration is based fundamentally on the religious principles of the “Shari’ah,” which diverges significantly from International Human Rights Standards.³¹ The Organization of the Islamic Conference Human Rights in Islam has been sanctioned under the Qur’an and are permanent, perpetual, and eternal. The life of women under Islam is accepted and understood only by reflecting on and being influenced by the Qur’an.³²

Many religiously based rules govern the physical exposure of women patients to male physicians or nurses. A pervasive culture of silence influences the way women perceive their bodies and health and circumscribes women’s “health-seeking behaviors.”³³ Segregating women strictly on the basis of their gender is often encouraged. There are current discussions of the creation of single-gender hospitals, set up to cater to women only. Implementation of the same-sex health care delivery system is in line with Islamist religious philosophy encouraging the separation of women from men in a medical environment.³⁴

5.2 Breast cancer in the Middle East

In Egypt, breast cancer represents 35.1% of all cancer in women, with the highest overall incidence in women ages 50 to 62. In a study with 600 women, 80% had limited knowledge and no education. Younger women (13%) had higher levels of education and were more knowledgeable about cancer. Among less educated women, 59% perceived cancer as an incurable disease connected with fear and fatalistic attitudes.³⁵

Similar to Qatar, the United Arab Emirates reports breast cancer as the number one killer of women.³⁶

Women in Arab countries must be encouraged to recognize and verbalize their health care needs. As Huda Zurayk, dean of the faculty of Health Sciences of the American University of Beirut, states:

“In aspiring to gender equality, it becomes particularly significant to listen carefully to the traditionally muted voices of women. What they tell us will present a different perspective to internationally determined program priorities, which should focus on women’s need for change, and their challenges to pursue a higher quality of their health and their lives.”³⁷

On her speech at the first ever “Youth Takeover” of the UN, Malala Yousafzai, a young education advocates from Pakistan stated:

“...I raise up my voice - not so I can shout, but so that those without a voice can be heard... No one will be able to silence us ... not now, and not ever...”³⁸

6 Implementing Declarations into Practical Clinical Care Changes Globally- The Palliative Care World Health Organization Experience

Over a million people die each week worldwide, and 75% do so without access to essential medicines needed to relieve suffering. The need for palliative care is estimated at 40 million people each year, half of them at the end of life. When we include families, always admitted along with patients to palliative or hospice care services, the number jumps to at least 100 million annually. The majority of these patients are older, but at least 6% are children. Seventy-eight percent live in low- or middle-income countries, and the vast majority (93.5%) suffer from noncommunicable diseases.²¹

On May 24, 2014, the World Health Assembly, the governing body of the World Health Organization, unanimously passed a resolution focused entirely on palliative care.³⁹ Titled “Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course,” the resolution calls on all governments to ensure the availability of palliative care as an essential component of all health care systems. The passage of that resolution took deliberate advocacy over a 3-year period.

Palliative care is not specifically codified in treaty as a human right; however, it can be inferred from important covenants and is supported by a number of international declarations. The International Covenant on Economic, Social, and Cultural Rights calls for the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (Article 12.1, 2000).⁴⁰

While palliative care is not specifically mentioned in the statement, the committee overseeing the International Covenant on Economic, Social, and Cultural Rights issued a general comment on the right to health that includes a number of core obligations of all signatory nations, irrespective of resources (2000). When it comes to palliative care, it is clear that patients with life-limiting illness should have access to appropriate health care and basic medications for symptom control and terminal care, necessitating the inclusion of palliative care in national health care policies.

The World Health Assembly resolution calls on all countries to improve access to palliative care as a core component of all health care systems, emphasizing primary and community/home-based care. Countries are asked to develop and strengthen policies that integrate palliative care into health systems; to ensure adequate domestic funding and human resources; to support families, volunteers, and care-givers; to integrate palliative care into all health professional education at all levels; to assess domestic need for care including access to essential medicines; to review and revise drug control legislation; to partner with civil society; and to integrate palliative care into plans for prevention and control of noncommunicable disease. The resolution also calls on the World Health Organization to monitor the global situation, work with other United Nations bodies to promote the availability and accessibility of essential medicines, develop guidelines and tools on palliation in health systems, encourage countries to adequately fund palliative care programs and research, and report back in 2016.

Palliative care and PSO are closely related fields, and while PSO can directly benefit from this resolution, there are some lessons learned on international advocacy for PSO. These include demonstrating evidence of the need for PSO, building coalitions and country-level support, identifying external champions, working with country delegations to the United Nations, being persistent and assertive, and, most importantly, paying very close attention to the implementation of actions⁴ on the part of the international community for the benefit of those we serve.

7 Conclusion

The *IPOS Lisbon Declaration: Psychosocial Cancer Care as a Human Right* presents an important call to action for psycho-oncology health care providers and cancer organizations across the globe. This declaration provides a necessary foundation to expand human rights beyond ensuring palliative care and pain treatment to psychosocial care delivered throughout the entire cancer treatment trajectory. Human rights ethics in certain parts of the world, such as Africa and the Middle East, have been cited to highlight tremendous challenges we must overcome in our efforts to ensure that quality cancer standards in the field of psycho-oncology are universally adopted for patients across the life span. Strategic efforts to develop this declaration through the IPOS Human Rights Task Force have been reviewed, with notable support from the Union for International Cancer Control and recognition from World Health Organization of IPOS as a nongovernmental organization. Furthermore, IPOS has recently revised the Statement on Standards and Clinical Practice Guidelines in Cancer Care to incorporate the *Lisbon Declaration*, which is an important step forward in bolstering the impact of this standard with the added value of a human right.

Endorsement of this updated standard is being sought worldwide, from national and international organizations and agencies who aim to improve cancer care and clinical outcomes for cancer patients. This requires a commitment on the part of individuals, cancer organizations, advocacy groups, and other stakeholders to develop useful strategies and engage policy makers to support legislative efforts that will ensure psychosocial cancer care is recognized as a fundamental human right.

Beyond legislation, there are further needs to advocate for improvements to access and availability of high-quality psychosocial care and provision of adequate resources to support such services and training of psycho-oncology professionals. The IPOS and its Federation of National Psycho-oncology Societies will continue to champion this cause. The IPOS worldwide community plays a vital role in this process through our collective responsibility towards disseminating this message and fostering its implementation, both to countries where psychosocial care is already widespread and to those nations where the critical importance of incorporating psycho-oncology services is just beginning to be recognized.

⁴For instance, providing technical support and monitoring each country's implementation of actions concerning access to PSO after reaching agreement at the international level (eg, World Health Assembly resolution) and publishing reports annually can be a way to keep pressure on responsible parties for its implementation.

Acknowledgments

L.G. and D.F. express gratitude to Drs Philip Odyio and Chioma Asuzu for their inputs on situations in African countries.

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Table 1

Self-reported level of development in psychosocial oncology practice among 25 countries (out of 28) belonging to the IPOS Federation of National Psycho-oncology Societies

Category	Description	N (%)	Countries
1	No known psychosocial oncology care activity	0 (0)	
	Unable to identify any psychosocial care activity in the country		
2	Capacity building activity	0 (0)	Kenya ^a
	Evidence of initiatives designed to create organizational, workforce, and policy capacity for psychosocial oncology care services to develop, although no service has yet been established		
3a	Isolated care provision	6 (24)	Romania, Slovenia, Spain, Brazil, Korea, Nigeria
	Development of psychosocial oncology care activism patchy in scope and not well supported		
3b	Generalized care provision	5 (20)	Lithuania, Portugal, Sweden, China, New Zealand
	Development of psychosocial oncology care activism, numerous locations with the growth of local support in those areas		
4a	Preliminary integration into mainstream service provision	10 (40)	Austria, France, Italy, Netherlands, Poland, Switzerland, Canada, USA, Israel, Taiwan
	Development of a critical mass of psychosocial oncology care activism in numerous locations and a variety of psychosocial oncology care providers and types of services; limited impact of psychosocial oncology service care upon policy		
4b	Advanced integration into mainstream service provision	4 (16)	Germany, UK, Australia, Japan
	Development of a critical mass of psychosocial oncology care activism in a wide range of locations; unrestricted availability of multiple aspects of psychosocial oncology care; substantial impact of psychosocial care upon public health policy		

^aKenya is not yet a member of the Federation but contributed to the survey, as a member of IPOS.