Communication in person-centered services:

Psychosocial support and communication needs in BC patients

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Founded in 1984, IPOS was created to foster the science and practice of psychosocial oncology to improve the care of people affected by cancer worldwide.

IPOS promotes global excellence in psychosocial care of people affected by cancer through partnerships, research, public policy, advocacy and education.

Through its Federation, IPOS represents more than 7,000 professionals in more than 60 countries.

www.ipos-society.org
Impact of Cancer and its consequences

Emotional and Psychological problems
- fear, sadness, worries, despair, loss of autonomy and control, change of self-image, uncertainty

Family and interpersonal
- uncertainty regarding social roles and tasks, separation from partners, children

Physical symptoms and functional problems
- pain, fatigue, dysfunction, psychosomatic symptoms, disabilities

Existential and spiritual problems
- Confrontation with the mortality of one’s own life, search for meaning, consolation; spiritual, religious, philosophical explanations

Social, financial, and occupational strain
- Responsibility of important social and occupational functions, new dependencies

Problems with the health care system
- Impersonal treatment, lack of time, lack of intimacy, terminology hard to understand

Koch & Mehnert, IPOS 2005
IPOS online curriculum: www.ipos-society.org

L Travado, CCC 2015
DISTRESS CONTINUUM

Normal Distress

adaptation

35 - 45%

Sub-sindrome

15-20%

Severe Distress

Psychosocial morbidity

25-45%

Worries

Fears

Sadness

Maladjustment

Anxiety

Depression

(Breast Cancer = 32 %; ABC = 42%)

Adapted from J.Holland, IPOS, 2005
IPOS online curriculum: www.ipos-society.org

L Travado, CCC 2015
## Risk factors for psychosocial distress

The following checklist can be used to identify cancer patients at a higher risk of psychosocial distress.

<table>
<thead>
<tr>
<th>Individual features</th>
<th>Disease/treatment factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Younger age</td>
<td>✓ Advanced stages of disease</td>
</tr>
<tr>
<td>✓ Single, separated, divorced, widowed</td>
<td>✓ Poorer prognosis</td>
</tr>
<tr>
<td>✓ Living alone</td>
<td>✓ More treatment side-effects</td>
</tr>
<tr>
<td>✓ Having children younger than 21 years</td>
<td>✓ Greater functional impairment and disease burden</td>
</tr>
<tr>
<td>✓ Economic adversity</td>
<td>✓ Lymphoedema</td>
</tr>
<tr>
<td>✓ Poor marital functioning</td>
<td>✓ Chronic pain</td>
</tr>
<tr>
<td>✓ Past psychiatric treatment especially depression</td>
<td>✓ Fatigue</td>
</tr>
<tr>
<td>✓ Cumulative stressful life events</td>
<td></td>
</tr>
<tr>
<td>✓ History of alcohol or other substance abuse</td>
<td></td>
</tr>
<tr>
<td>✓ Female gender</td>
<td></td>
</tr>
<tr>
<td>✓ Disease/treatment factors</td>
<td></td>
</tr>
</tbody>
</table>
Consequences of Psychological Morbidity in Cancer Patients: impact on Clinical outcomes

- Deterioration of Quality of Life
- Reduced compliance w/ treatment
- Less efficacy of chemotherapy
- Higher perception of pain and other symptoms
- Shorter survival expectancy
- Longer hospital stay and increased costs
- Burden for the family
- Higher risk of suicide


Adapted and updated from Grassi & Yosuke
IPOS online curriculum: www.ipos-society.org

L Travado, CCC 2015
Influence of psychological response on breast cancer survival:
10-year follow-up of a population-based cohort

A randomized controlled trial of cognitive-behavioral stress management in breast cancer: survival and recurrence at 11-year follow-up

Jamie M. Stagl1 · Suzanne C. Lechner2,3 · Charles S. Carver3,4 · Laura C. Bouchard4 · Lisa M. Gudenauf4 · Devika R. Jutagir4 · Alain Diaz5 · Qilu Yu6 · Bonnie B. Blomberg3,5 · Gail Ironson4 · Stefan Glück7 · Michael H. Antoni2,3,4

Fig. 3 Breast cancer-specific survival difference in study groups. Differences between study groups (CBSM vs. control) with Cox proportional hazards models on time to breast cancer-specific mortality controlling for covariates: age, HER2/neu, endocrine therapy, and tumor size. “Cumulative Survival” indicates disease-free interval.
Median survival time was **53.6 months** for women with decreasing CES-D scores over 1 year and **25.1 months** for women with increasing CES-D scores. Neither demographic nor medical variables explained this association.

**Decreasing depression symptoms over the first year were associated with longer subsequent survival for women with MBC in this sample.**

Psycho-oncology services provide effective (evidence-based, RCT's) interventions for:

(a) preventing or reducing the distress and psychosocial morbidity associated w/ cancer

(b) improving patients’ skills to cope with the demands of treatment and the uncertainty of the disease and improving their Quality of Life

(c) improving clinical outcomes

>> And are cost effective as well as general health costs reductive

Psycho-oncology services are an important element of high-quality cancer care
Clinical practice guidelines for the psychosocial care of adults with cancer
IPOS Statement on Standards and Clinical Practice Guidelines in Cancer Care (updated w/ Lisbon Declaration)

- 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 after temperature, blood pressure, pulse, respiratory rate and pain.

Endorsed by UICC and 75 cancer organizations worldwide
Clinical practice guidelines: NCCN Distress Thermometer & Problem List

The Distress Thermometer

First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

- Child Care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Dealing with children
- Dealing with partner
- Dealing with close
- Friend/relative
- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities
- Spiritual/religious concerns
- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhoea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry itchy
- Sleep
- Tingling in hands/feet

Other problems

L Travado, CCC 2015
Today, it is not possible to deliver good-quality cancer care without using existing approaches, tools, and resources to address patients’ psychosocial health needs. All patients with cancer and their families should expect and receive cancer care that ensures the provision of appropriate psychosocial health services. This report recommends ten actions that oncology providers, health policy makers, educators, health insurers, health plans, quality oversight organizations, researchers and research sponsors, and consumer advocates should undertake to ensure that this standard is met.
RECOMMENDATIONS FOR ACTION

Recommendation 1: The standard of care. All parties establishing or using standards for the quality of cancer care should adopt the following as a standard:

All cancer care should ensure the provision of appropriate psychosocial health services by

- facilitating effective communication between patients and care providers;\(^4\)
- identifying each patient’s psychosocial health needs;
- designing and implementing a plan that
  - links the patient with needed psychosocial services,
  - coordinates biomedical and psychosocial care,
  - engages and supports patients in managing their illness and health; and
- systematically following up on, reevaluating, and adjusting plans.
The way in which health care professionals communicate with patients has implications for:

- Quality of relationship provider-patient
- Patient’s adjustment
- Patient’s compliance with treatment
- Patient’s clinical outcomes
- Patient’s satisfaction
- Professional’s satisfaction and well-being
- Health care economy

Good communication skills facilitates addressing patients’ concerns and needs, provide basic emotional support, detection of emotional problems and a patient-centered care model.

CST improves skills.

Armstrong & Holland, 2004; Baile et al., 1997; Fallowfield and Jenkins, 1999, 2004; Maguire, 1999; Razavi and Delvaux, 1997; Mager and Andrykowski, 2002; Parle et al., 1997; Roberts et al., 1994; Stewart, 1984, 1996; Kinnersley et al., 1999; Jenkins and Fallowfield, 2002; Levinson and Roter, 1995; Travado et al. 2005; Kissane et al. 2011.

L Travado, CCC 2015
Doctor’s knowledge (meanings about: health, disease, treatment, future, QoL, etc.)

Specialist in medicine

Patient’s knowledge (meanings about: health, disease, treatment, future, QoL, etc.)

Specialist in their own life

Dialectics

Dialectics between doctor and patient: open discussion by the doctor/healthcare professional about the treatment options, their benefits and risks, and the patient about their preferences, needs, concerns and expectations >> patient-centered care approach

L Travado, CCC 2015
Effective patient-clinician communication is central to the delivery of high-quality care.

It is crucial in the cancer setting where patients have to deal with stress, uncertainty, complex information, and life-altering medical decisions.
To attain optimal results, a patient-centered comprehensive interdisciplinary approach and optimal psycho-social care should be implemented in routine cancer care, rehabilitation, post-treatment and follow-up for all cancer patients (point 5);

Stresses the healthcare and psychosocial needs of children and their families (point 8)

Emphasizes that cancer treatment and care is multidisciplinary, involving the cooperation of oncological surgery, (...) as well as psycho-social support and rehabilitation and when cancer is not treatable, palliative care. (point 11)

Take into account the psycho-social needs of patients and improve quality of life for cancer patients should be taken into account through support, rehabilitation and palliative care (point 19)
EPAAC - WP7 on Healthcare Psychosocial Oncology Action

Preliminary results from the European survey

N=27/30 countries (87%)

National Cancer Control Plan (NCCP)

(a) Psychosocial Care included in 21/27 NCCP (78%)
(b) Budget only 10/27 (37%) for these clinical services!!

L Travado, CCC 2015
1. **NCCP: Provision responsibility of PSOC**

![Provision of psychosocial care responsibility diagram]

- Cancer patients organizations
- Charities or NGO’S
- Locally/Hospital budget
- Regionally (regional administration)
- Nationally (Ministry of Health)

**Fig. 1 Provision of psychosocial care responsibility**

Preliminary results from the European survey (27 countries)
2. Structure and resources of Psychosocial Care Delivery

Figure 2. Where PSOC is more likely provided

- Cancer Centres
- University Hospitals
- General Hospitals
- Rehabilitation Centers
- Charities or NGOs
- Cancer patient organizations
- Primary Care Facilities
- Community Services
3. Clinical Guidelines for Psychosocial cancer care and official certification

- Only 8 countries (30%) with Nat’l recommended clinical guidelines for PSOC

- Only 6 countries (22%) with PSOC official certification (e.g. University, National Health Agency Ministry)

Travado et al. Psycho-oncology (in press)
4. Education (cont.)

- **CST provided during medical education** in 17/27 countries (63%)

- **CST resources for healthcare professionals** in 19/27 countries (70%)

- **CST as a priority for training healthcare professionals** 18/27 (67%)

Travado et al. Psycho-oncology (in press)
4. Education (cont.)

(d) Main training priorities in psychosocial cancer care in your country
Conclusions of the EPAAC Survey

**EU improvement:**

- recognition of psycho-oncology and psychosocial cancer care as part of routine cancer treatment
- inclusion in NCCPs

**Areas to improve:**

- reducing inequalities among countries
- budget for psycho-oncology services and its development
- training and certification in PSOC
- having a national policy concerning PSOC with a recommendation for the use of existing clinical guidelines
- implementation of these standards
- Role of Nat’l P-O societies and in lobbying with Patients’ Associations

Travado et al. Psycho-oncology (in press)
Psychosocial Oncology Care

Luzia Travado, Miriam Dalmas

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Programme elements
NCCP needs to include the following elements for quality psycho-oncological care:

- **Training** of health care professionals in the psychosocial aspects of cancer
- Inclusion of routine *Screening for Distress*, the 6th Vital Sign* of cancer patients
- **Employ evidence-based treatments** for symptoms and psychosocial needs identified through Screening for Distress
- Development of **minimum practice standards in Psycho-oncology Services**
- Implementation and **integration of psycho-oncology programmes into cancer multidisciplinary teams (MDTs)**
- **Engagement of resource procurement sector and service providers** to ensure that *comprehensive cancer care includes psychosocial care as standard*
Training of healthcare professionals in psychosocial aspects and communication skills

Training in communication skills (CST) contributes to better patients’ clinical outcomes and can reduce cancer physicians’ burnout.

Promoting effective communication between patients, caregivers and healthcare professionals can be achieved through:

- Including CST in undergraduate and postgraduate curricula for physicians, nurses, and other allied health care professionals in cancer care
- Continued professional development programmes in psychosocial oncology in all cancer settings
### 3. Indicators

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<tr>
<th>Types of Indicators</th>
<th>Core</th>
<th>Additional/Supplementary</th>
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<tbody>
<tr>
<td>Structural</td>
<td>• Inclusion of the psychosocial care services for cancer patients in the National Cancer Control Plan</td>
<td>• Number of cancer care facilities with psychosocial care services per number of cancer care facilities in the country</td>
</tr>
<tr>
<td></td>
<td>• Existence of the psychosocial care services/units in the national healthcare system</td>
<td>• Availability of post-graduation courses and/or MSc courses in psycho-oncology provided by Universities</td>
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<td></td>
<td>• Number of psychosocial care professionals working in cancer care services</td>
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<td>• Continuity in participation of psychosocial care specialists in the multi-disciplinary team meetings per service and per hospital treating cancer patients</td>
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<td></td>
<td>• Inclusion of <strong>communication skills training (CST)</strong> in curricula and continued professional development programmes for medical doctors and nurses:</td>
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<tr>
<td></td>
<td>• Undergraduate curricula</td>
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<td></td>
<td>• Post-graduate curricula</td>
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<tr>
<td></td>
<td>• Having a budget for psychosocial care services</td>
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| Process             | • Proportion of cancer patients that are screened - routinely and on a regular basis - for distress against the number of cases of cancer per year | • Cost-offset analyses to clarify benefits                                               |
|                     | • Proportion of cancer patients that receive psychosocial care                                                       |                                                                                           |

| Outcome             | • Patient satisfaction                                                                                              | • General well-being                                                                    |
|                     | • Quality of life                                                                                                  |                                                                                           |
Thank you!
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