Improving outcomes for patients by attending to their distress

Luzia Travado
Central Lisbon Hospital Centre – Hospital S. José, Portugal
International Psycho-Oncology Society
luziatravado@netcabo.pt

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“The emotional trauma of having cancer diagnosis and treatment can be as potentially harmful for the patient as the disease itself”.

Impact of Cancer and its consequences

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

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

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

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

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

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

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

Patient

Adapted from Koch & Mehnert, 2005, IPOS online curriculum www.ipos-society.org
We know that...(scientific evidence)

1. 50% of cancer patients suffer from distress and some will develop psychological morbidity

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## DISTRESS CONTINUUM

### Normal Distress
- Adaptation: 35 - 45%

### Sub-syndrome
- 15-20%

### Severe Distress
- Psychosocial morbidity: 25 - 45%
- Maladjustment
- Anxiety
- Depression

*Adapted from J. Holland, IPOS, 2005*
Epidemiology of Psychological Morbidity in cancer patients

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Screening or Clinical Interview Rates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety disorders</td>
<td>Screening up to approx. 50%, clinical interview up to approx. 30%, in terminally ill patients up to 80%</td>
</tr>
<tr>
<td>Depression</td>
<td>Screening up to approx. 50%, clinical interview up to approx. 15%, in terminally ill patients up to 77%</td>
</tr>
<tr>
<td>Adjustment disorders</td>
<td>Screening or clinical interview up to approx. 50% (frequently mixed anxiety and depressed mood)</td>
</tr>
<tr>
<td>Post-traumatic stress disorder</td>
<td>Screening or clinical interview up to approx. 30%</td>
</tr>
<tr>
<td>Cognitive disorders (delirium)</td>
<td>Screening or clinical interview up to approx. 85% in terminally ill patients</td>
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adapted from Koch & Mehnert, IPOS 2005
IPOS online curriculum, www.ipos-society.org
Prevalence of Anxiety and Depression in differing periods of time since diagnosis

N=1083 breast cancer patients, representatively selected from the Hamburg Cancer Register

18 to 24 months: up to 36 months: up to 48 months: up to 60 months: more than 60 months after diagnosis

Anxiety Screening:
in 36% of the patients an anxiety disorder is possible or probable

Depression Screening:
in 21% of the patients depression is possible or probable

HADS Screening

adapted from Koch & Mehnert, IPOS 2005
IPOS online curriculum, www.ipos-society.org
2. Psychosocial morbidity has significant negative clinical consequences

> yet ~70% of this suffering goes unrecognized...
Consequences of Psychosocial Morbidity in Cancer Patients

- 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 from Grassi & Yosuke, IPOS, 2005

www.ipos-society.org
3. **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

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

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### RCTs in Psycho-Oncology Interventions

<table>
<thead>
<tr>
<th>AUTHORS</th>
<th>SAMPLE</th>
<th>INTERVENTION</th>
<th>OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linn et al. (Cancer, 1982)</td>
<td>120 patients in advanced phase</td>
<td>Counselling vs. control</td>
<td>Improvement in QoL</td>
</tr>
<tr>
<td>Weisman et al. (Cancer, 1984)</td>
<td>117 outpatients</td>
<td>Psychotherapy vs Relaxation vs control</td>
<td>Decrease in stress symptoms and increase in problem-solving skills</td>
</tr>
<tr>
<td>Greer et al. (BMJ, 1992)</td>
<td>174 patients w/ psychological disorders</td>
<td>Short-term psychotherapy (APT) vs traditional care</td>
<td>Decrease in anxiety &amp; depression, improvement in coping and QoL</td>
</tr>
<tr>
<td>Spiegel et al. (JNCI, 1998)</td>
<td>125 metastatic breast cancer patients</td>
<td>Group Psychotherapy vs control</td>
<td>Decrease in anxiety, depression, pain, improvement in QoL</td>
</tr>
<tr>
<td>Goodwin et al. (N Eng J Med, 2001)</td>
<td>235 metastatic breast cancer patients</td>
<td>Group Psychotherapy vs control</td>
<td>Decrease psychological stress symptoms</td>
</tr>
<tr>
<td>Simpson et al. (Ca Pract, 2001)</td>
<td>Breast cancer patients</td>
<td>Group psychotherapy vs control</td>
<td>Psychosocial improvement + 23,5% reduction of health care billings !</td>
</tr>
</tbody>
</table>
Distress Management

The NCCN Guideline for Distress Management: A Case for Making Distress the Sixth Vital Sign

Psychosocial care of patients has traditionally been seen as separate from routine medical care and has been criticized as being "soft" and lacking evidence. This traditional perspective continues in many settings, despite the fact that patients and families, when asked, state that emotional care is highly valued. The question of how to integrate psychosocial care into routine cancer care has also been an issue, partly because of the stigma associated with cancer.

In 1997, the National Comprehensive Cancer Network (NCCN) established a multidisciplinary panel to examine this problem. Because patient and physician attitudes toward pain can pose similar barriers to care as can distress, the panel used as a model the rating system for assessing pain that resulted in successful improvement of pain management in the United States. The rating system's success seemed partly based on routinely using a single question to assess a patient's pain: "How is your pain on a scale of 0 to 10?" The system uses a score of 5 or higher as the indication to reassess pain medications or refer the patient to the pain management specialist.
• 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)
Psychosocial Oncology Action

- To implement a training strategy to improve psychosocial care and communication skills among health care providers in Europe

Hosted by the Institut Catalan of Oncology with the collaboration of IPOS as main partner

Key areas:
- Mapping the psychosocial needs and resources in EU countries
- Develop an educational training program to be replicated
- Pilot the training program in one underserved country

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IPOS New International Standard of Quality Cancer Care:

- **Quality cancer care today must integrate** the psychosocial domain into routine cancer care

- Distress should be measured as the 6th vital sign after temperature, blood pressure, pulse, respiratory rate and pain

Endorsed by UICC
IPOS, August 2010
• Psycho-oncology is considered today an important part of quality cancer care

• Evidence-based interventions reduce distress and psychological symptoms or morbidity associated with cancer and its treatment, enhances compliance with treatment and quality of life, contributing to improve patients’ clinical outcomes

• Psychosocial care is recommend to integrate routine cancer care

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Collaborating and working together is critical to put EU recommendations and clinical guidelines into national policies and practice, to improve patients’ outcomes.

Add Quality to Life Project

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Communication and Interpersonal Skills in Cancer Care by Walter Baile, MD (USA)
Anxiety and Adjustment Disorders in Cancer Patients by Katalin Muszbek, MD (Hungary)
Distress Management in Cancer Patients by Jimmie C. Holland, M.D, USA
Depression and Depressive Disorders in Cancer Patients by Luigi Grassi, MD (Italy) and Yosuke Uchitomi, MD, P.D (Japan)
Psychosocial Assessment in Cancer Patients by Uwe Koch, MD, PhD & Anja Mehnert, PhD (Germany)
Cancer: A Family Affair by Lea Baider PhD (Israel)
Loss, Grief and Bereavement by David Kissane MD (Australia)
Palliative Care for the Psycho-Oncologist by William Breitbart MD USA)
Ethical Implications of Psycho-Oncology by Antonella Surbone MD, PhD, FAC (Italy)