



**2018**

**28-30 JUNE**  
**VIENNA, AUSTRIA**

**SUPPORTIVE CARE**  
**MAKES EXCELLENT**  
**CANCER CARE POSSIBLE**



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Emotional support during Chemo

**Paz Fernández-Ortega. PhD, MSc, RN, BPsych**  
*Chair of Education MASCC SG*  
*Nursing Research Coordinator. Institute Català d'Oncologia*  
*Barcelona- Spain. Mail: [mfo@iconcologia.net](mailto:mfo@iconcologia.net)*



**2018**

**28-30 JUNE**  
**VIENNA, AUSTRIA**

**SUPPORTIVE CARE**  
**MAKES EXCELLENT**  
**CANCER CARE POSSIBLE**



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Let's talk about...

- 1 Emotional support
- 2 Multidimensionality
- 3 Intention & perception
- 4 Special situations
- 5 Who is at risk
- 6 Tools and best interventions
- 7 Take home message...

*Paz Fernández Ortega PhD, MSc, RN. Education SG*



**2018**

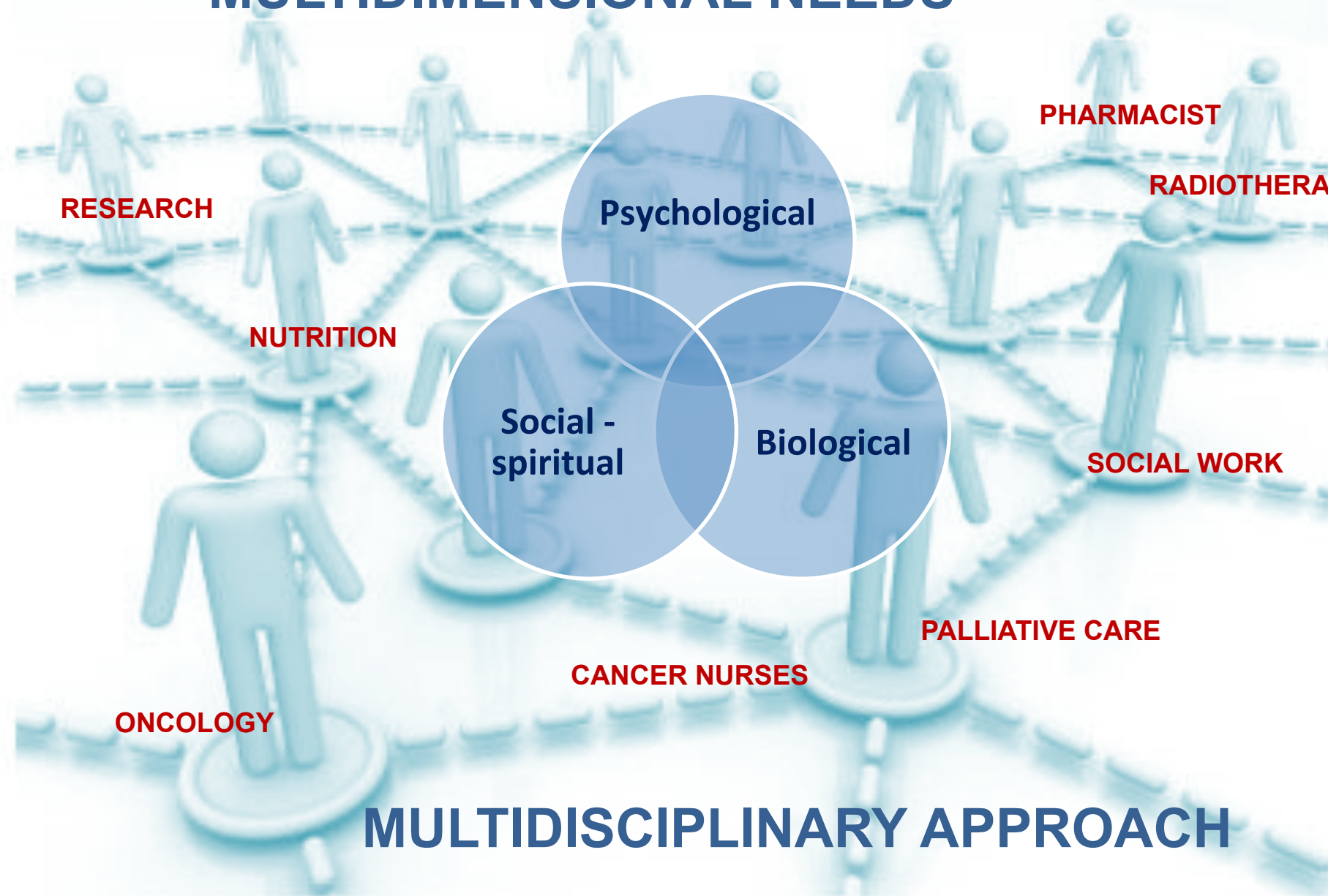
28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# MULTIDIMENSIONAL NEEDS



# MULTIDISCIPLINARY APPROACH

# Chemotherapy intention always is/ should be to bring benefit to patient

1

Effectivity

2

Subjective- cognitive perception benefit/ non benefit



**But, how patients perceive this?**

**Signals coming from professionals, nurses & family- caregivers**







**2018**

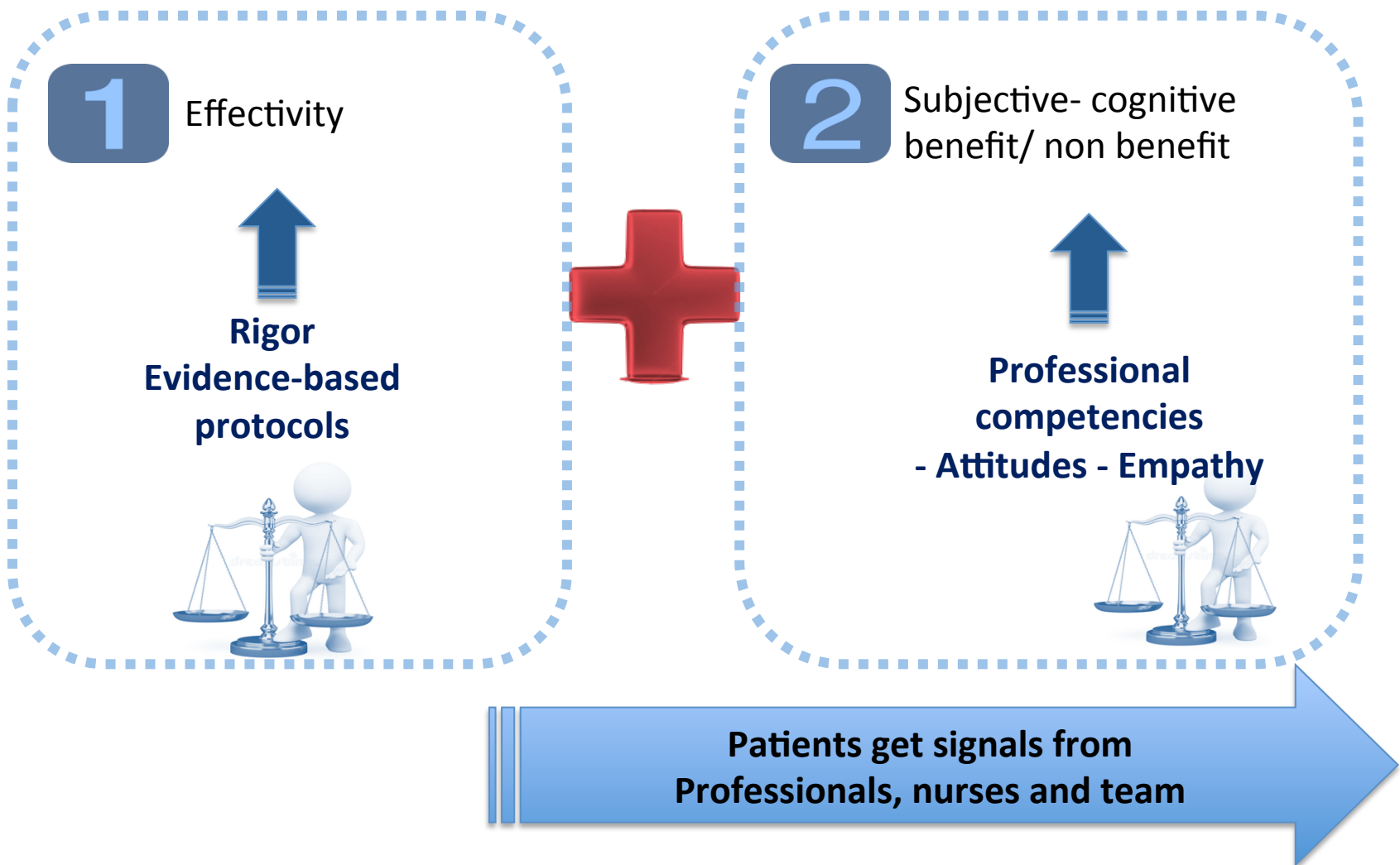
**28-30 JUNE  
VIENNA, AUSTRIA**

**SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE**



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Outcomes & benefit perceived for patients



# What is emotional support

- **Emotions** refer to feelings in pre-chemotherapy
  - Feelings as fear, frustration, guilty...

## Patients need:

- Receive treatment information
- Receive instrumental information and..
- Receive affective information
  
- Sometimes one is substituting the other



Balancing all..



**2018**

**28-30 JUNE  
VIENNA, AUSTRIA**

**SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE**



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

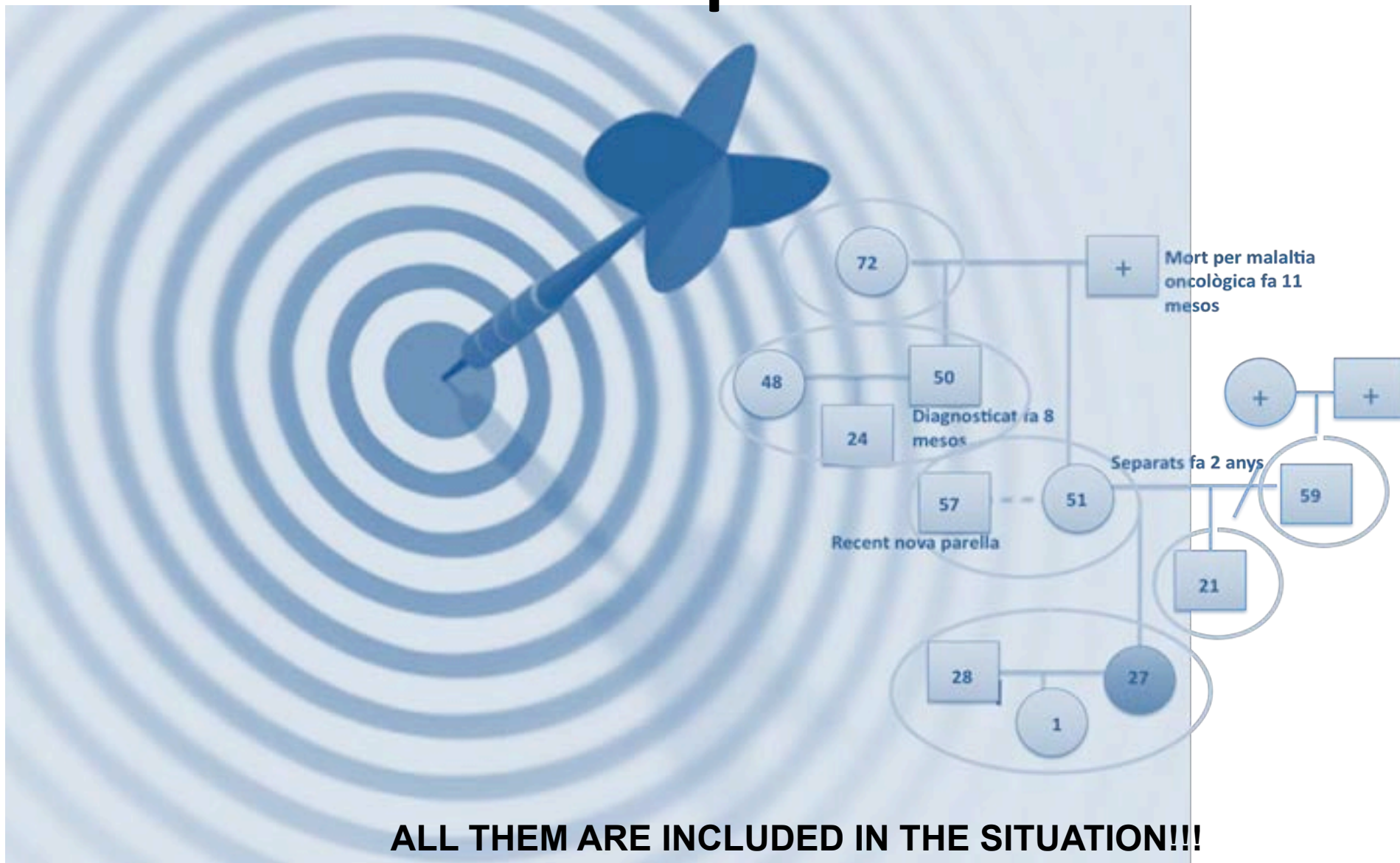
# Vulnerability situation



**Majority of patients receiving  
Chemotherapy; Adjuvant or Palliative and/or  
in clinical trials Phase I**

- Situation of suffering
- Threatening situation
- Loss of control
- Impact situation
- Feeling of despair
- Fear
- Doubts
- Difficulties for communication
- Difficulties to keep the attention

# Who is our patient?



**ALL THEM ARE INCLUDED IN THE SITUATION!!!**

*Paz Fernández Ortega PhD, MSc, RN. Education SG*

**2018**  
28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE

**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER



# Physical needs interrelation:

- **Symptoms more prevalent:** asthenia, anorexia and loss of weight...
- Refractory situation of distress also causing 41-55% of cases.
- **Complex lesions:** external lesions, hemorrhagic, infections, odor...

## Consider **high complexity** if:

- **Low adherence in previous treatments**
- **Difficulty in medications management**
- **If using devices as pumps**

Advanced oncology nurse  
patient evaluation



# Physical needs, interrelation:

**Symptoms more prevalent:** asthenia, anorexia and loss of weight...

Refractory situation of distress also causing 41-55% of cases.

**Complex lesions:** external lesions, hemorrhagic, infections, odor...

Consider as **high complexity** if:

- **Low adherence in previous treatments**
- **Difficulty in medications management**
- **Lack of supportive medications ++**
- **If using devices as pumps or nasogastric or other**

## Alert if:



- High n° symptoms + high intensity
- High toxicity
- Low adherence
- Repetitive - hospitalization
- Patient age
- Emergencies situation
- Ending active treatment



2018

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



MASCC/ISOO  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER



2018

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



MASCC/ISOO  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Psychological needs

**Emotional suffering** is the result of **adaptation** to difficulties.

- It is a cognitive state
- Prognosis predictor. \*
- with a sense of threat for the personal integrity
- feeling of impotence -predestination
- lack of personal and psychosocial resources to cope
- feelings of loss of control
- hopelessness
- uncertainty.

Li L et al. (2017) Prognostic values of EORTC QLQ-C30 and QLQ-HCC18 index-scores in patients with hepatocellular carcinoma clinical application of health-related quality-of-life data. BMC Cancer.



**2018**

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Psychological needs

## Some data:

- Psychological problems (12–85 %)
- Information (6–93 %)
- Social problems (1–89 %)
- Spiritual(14–51 %) \*\*
- communication (2–57 %)
- Sexuality needs (33–63 %)

\* Harrison JD (2009) What are the unmet supportive care needs of people with cancer? **A systematic review.** Support Care Cancer 17:1117–1128

\*\*Jimenez-Fonseca P. 2018 The mediating role of spirituality (meaning, peace, faith) between psychological distress and mental adjustment in cancer patients. Support Care Cancer.



# Psychological needs

**Emotional suffering** is the result of **adaptation** to difficulties. **Do professionals check adaptation??**

High level of distress

- High demand of attention
- Low demand of attention

Meaning of the treatment

How patient use his coping strategies

Emotional and spiritual resources

Recent cases in same family

Degree of threat perceived

Higher risk personality disorders & history of psychiatric illness.



**Alert if:**

Advanced oncology nurse  
patient evaluation





2018

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



MASCC/ISOO  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Social - Family needs

- Living conditions and environmental.
- Role, relationships, family dynamic, relations in family.
- Self-care practices
- Values, beliefs and practices
- Resources and organization for care
- Financial and economic impact of disease

## COMPLEXITY CRITERIA:

- **caregiver claudication for caring**
- **increase burden of care**
- **not cover the caregiver needs**
- **lack of support**



**Alert if:**

Advanced oncology nurse  
patient evaluation



**2018**

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

## Which are patient 's expectation of chemo?



- ➔ Motivation & benefit expected for chemo.
  - **Is there many possibilities?**
  - **Is only the “last hope for patient”??**
- ➔ There is discordance between patient family
- ➔ Solidarity with the human being. Altruism

## What aspects can influence subjective perception patient/family during chemo or Clinical Trials?



### Patient - Family

- Personalized relationship
- Information received
- Shared decisions on treatment
- Proves & complementary tests
- Experience of inclusion / exclusion
- Proximity to the team
- Adjusted expectations
- Side-effects
- Accessibility in case of doubts
- Perception of meaning (legacy)







**2018**

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# What patients tell us about?:

- **Satisfaction with emotional support**
  - Definition: the extent to which patients feel they receive help to cope with emotions and stress/distress
  - **Stress - distress** increase during Chemo

Brandes K, et al. **Understanding the interplay of cancer patients' instrumental concerns and emotions.** *Patient Educ Couns.* 2017;100(5):839-845.



**2018**

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Existing tools?:

**Some tools** are purely informing or providing information – so they are attending patients' informational needs.

- Most focus in symptoms , not always cover emotional needs..
- Best: balancing the instrumental issues with the emotions

Tools with a holistic perspective:

- **CHEMOSUPPORT** – 2018 *Oncology Nursing Forum*, Coolbrandt et al.
- Short-Form Supportive Care Needs survey (**SCNS-SFM**) \*
- Effective follow-up post Chemotherapy; **Internet, video\*\***, **phone calls, APP, patients groups education, expert patient...**

\* Boyes A, (2009) Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *J Eval Clin Pract.*

\*\* Kinnane N. (2008) Evaluation of the addition of video-based education for patients receiving standard pre-chemotherapy education. *Eur J Cancer Care .*



**2018**

**28-30 JUNE  
VIENNA, AUSTRIA**

**SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE**



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Case: María

And chemotherapy...

*Paz Fernández Ortega PhD, MSc, RN. Education SG*



2018

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



MASCC/ISOO  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# María...

- Ms. M is an 77 year-old woman recently diagnosis with stage IV Pancreatic Cancer.
- She had remained in great health until her recent diagnosis, after which her energy had plummeted and she was spending over 50% day in sofa-bed.
- Overwhelmed with the sight of their loved one losing her strength with each passing day, her family had gone into panic.
  - “Couldn’t the doctors save her from this cancer?”
  - “Chemotherapy has helped so many, right?”
  - “We need to try something, doctor!”





2018

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



MASCC/ISOO  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# María...

- The patient herself was detached from the idea of battling the disease:
  - “I have lived a good life,” she would say, and take a passive distance in her treatment / illness.
  - This attitude further distressed the family: “it is like she is giving up.”
  - Upon request of the cancer nurse, oncologist evaluated the patient and took the time to discuss treatment options.
- The only remaining option was chemotherapy  
Surgery was no longer an option, and radiotherapy was not going to be particularly useful.



2018

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



MASCC/ISOO  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Maria...

- Patient and family were reluctant and did not know what chemotherapy really meant.
  - Would be useful an informative pamphlet of the potential chemotherapeutic drugs .....
  - Pamphlet explains: “Nephrotoxicity, neurotoxicity, thrombosis, rash, edema, risk of bleeding...”
  - Family long discussions:
    - chemotherapy is going to make her suffer more!”
    - “she is not going to give up like this!”
    - “if not chemotherapy then what?!”
- AND....“what if chemotherapy saves her life?!”



**2018**

**28-30 JUNE  
VIENNA, AUSTRIA**

**SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE**



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER



Now Chemo  
and....???



**2018**

28-30 JUNE  
VIENNA, AUSTRIA

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

# Some useful tips:

- **Sit, don't stand:** same level as pt.
- **Make eye contact.** Not to computer
- **Listen carefully:**  
**compassionate presence.**
- **Use plain, non-medical**
- **Use the patient's words.**
- **Slow down:** Speak clearly and moderate pace.
- **Limit and repeat content:** 3-5 key points and repeat them.
- **Ask patients to repeat** after the information given his language

- **Be specific and concrete:** Don't vague
- **Show graphics:** pictures or illustrations,
- **Include family members in discussion.**
- **Demonstrate how it's done.** Demonstration
- **Invite patient participation:**
  - “What questions do you have?” or “We discussed a lot of information. What can we review again?”
  - Don't: “Do you have any questions?”
  - Elicit questions from patients several times during an office visit.
- **Show that you have the time:**
- **Help patients prioritize questions.** long list
- **Remind patients to bring questions with them to appointments.**



<http://www.helphurttool.com/>

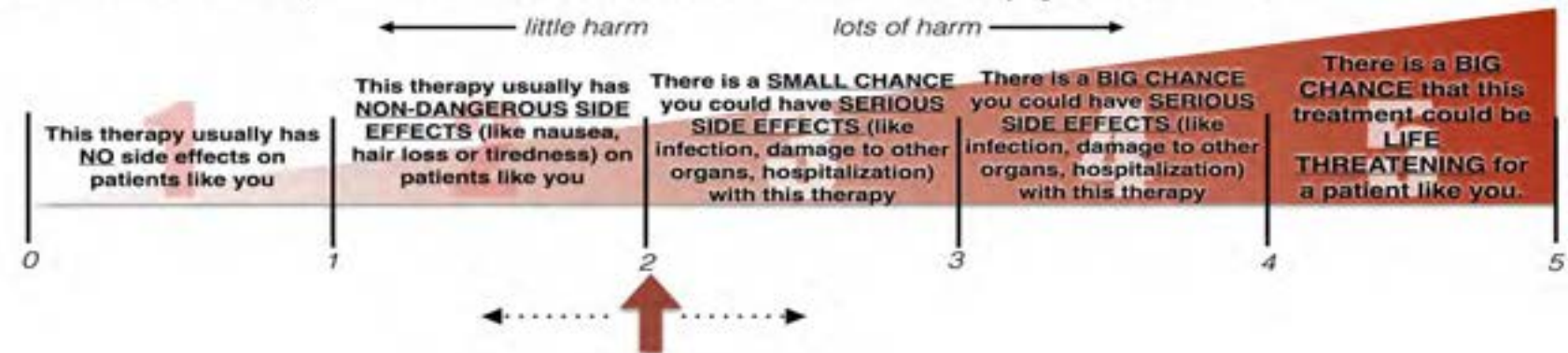
Zañartu **Help-Hurt** Tool  
for Therapeutic Decision-Making\*

\*© Monteliore Medical Center

From **1** to **5**, how much could this therapy **help** me?



From **1** to **5**, how much could this therapy **hurt** me?



**2018**  
28-30 JUNE  
VIENNA, AUSTRIA  
SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER



# Take home message...

- **Chemotherapy context + *distress***
  - Multidimensionality - multiprofessionals
  - Moments that increase complexity - first cycle
  - Persons more vulnerable; older, migrants, palliative, adolescents
  - Relapse; second- 3rd- 4th line. Clinical Trial - Finish treatment
- **Baseline assessment is a **good predictor of post survival and morbidity****
  - Professionals being alert on signs for distress
  - Being alert to complexity
  - Cognitive meaning attributed to Chemo
  - Tools and referral to expert professionals



Don't  
**FORGET!**



Don't  
**FORGET!**





**2018**

**28-30 JUNE**  
**VIENNA, AUSTRIA**

**SUPPORTIVE CARE**  
**MAKES EXCELLENT**  
**CANCER CARE POSSIBLE**



**MASCC/ISOO**  
ANNUAL MEETING ON  
SUPPORTIVE CARE IN CANCER

Questions?  
Suggestions?  
Discussions...

# Thanks!



**H** = Have  
**O** = Only  
**P** = Positive  
**E** = Expectations