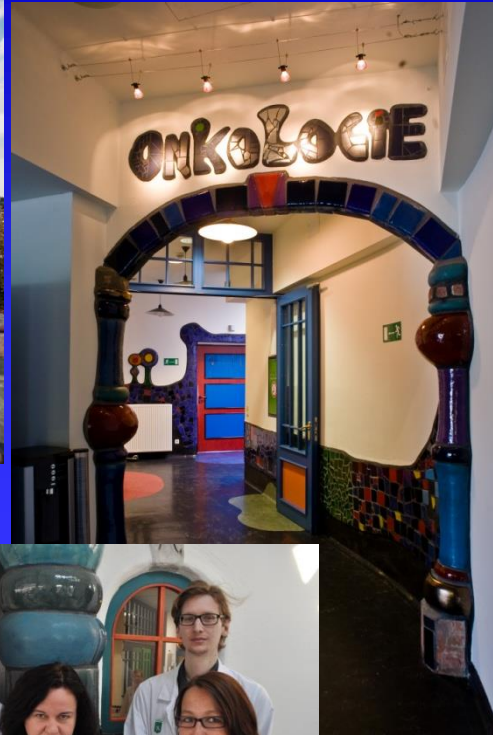


The Role of Psycho-Oncology

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NEW HORIZONS GIST 2018: 5. - 7. Sept. 2018 in Vienna/Austria





Parts of the presentation

- **Psychooncology – definition**
- **Why is psychological support needed and important**
- **Psychological interventions and techniques** - getting a short overview of basics and concepts of different psychosocial interventions
- **Psycho-Oncology – future directions** *for patients with GIST*

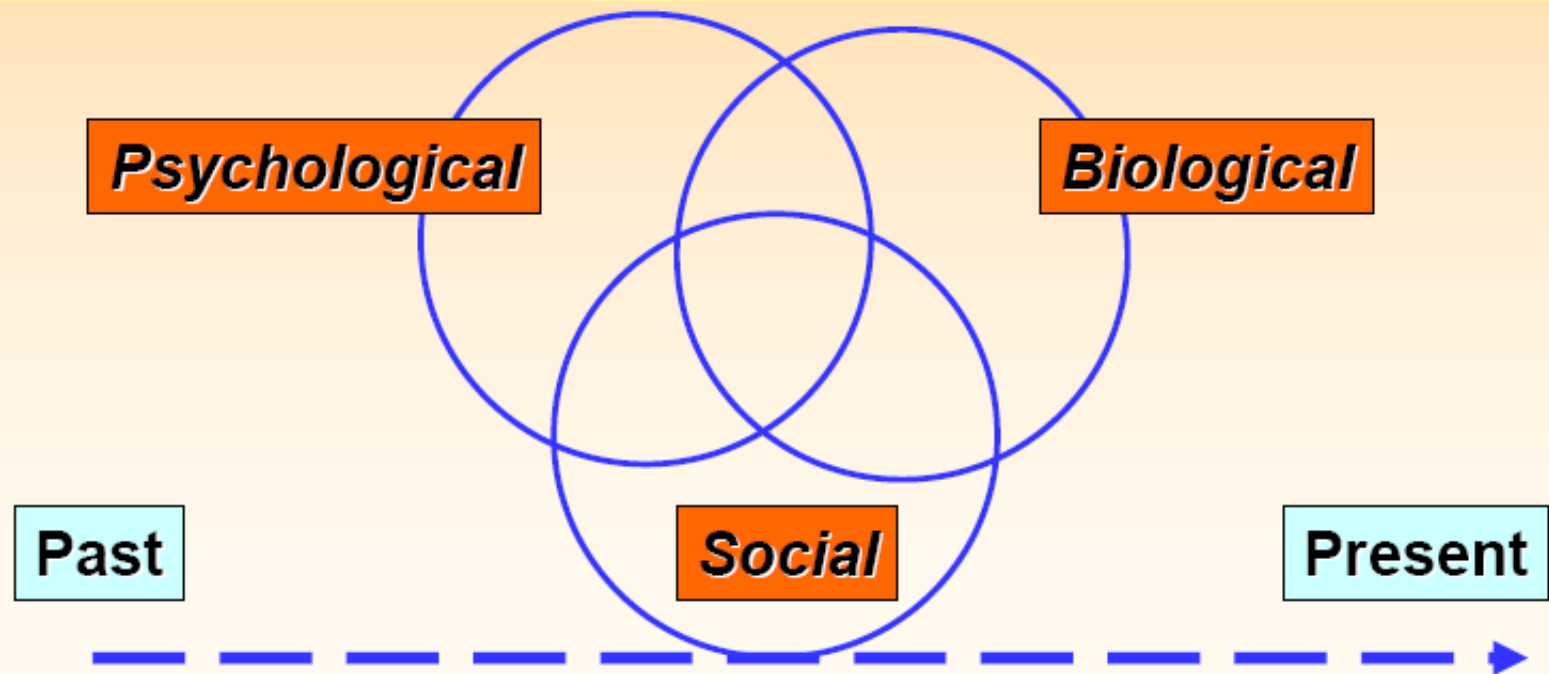
A new medical model

8 April 1977, Volume 196, Number 4286

SCIENCE

The Need for a New Medical Model: A Challenge for Biomedicine

George L. Engel



Definition

Psycho-Oncology is a growing area of oncology, focusing on the psychological, social and emotional impact of cancer on patients and caregivers, and on health behaviour. Psycho-Oncology addresses the two psychologic dimensions of cancer:

- The Psychosocial dimension
- The Psychobiologic dimension

The Psychosocial dimension

The Psychosocial dimension refers to the psychologic response of patients to cancer at all stages of disease, as well as that of their families and their caretakers.

This aspect impacts on the care of all patients, irrespective of age, site of cancer, or treatment.

Jimmie C. Holland, MD & Jane Gooen-Piels, PHD (2000), Cancer Medicine

The Psychobiologic dimension

The second dimension consists of the psychological, behavioral, and social factors that influence risk, detection, and survival.

For example the once 'social' past time of smoking may influence risk, detection and survival.

Psycho-Oncology in practice

In everyday practice, the role of Psycho-Oncology is about safeguarding the psychological health of cancer patients by:

- Recognising the unique psychological needs of cancer patients and how this impacts upon QoL
- Assessing and monitoring the psychological state of cancer patients
- Facilitating patient adaptation following diagnosis, reducing distress and psychosocial morbidity, improving patients coping skills and QoL through Psycho-Oncology interventions tailored to patients needs
- Fostering patient-centred care
- Facilitating communication to ensure patients and carers receive adequate information on their condition, treatment and resources

Education – Clinical – Research

Key stakeholders

Psycho-Oncology incorporates a range of stakeholders including:

- Oncologists
- GPs
- Nurses
- Psychologists
- Psychiatrists
- Social workers
- Religious representatives
- Volunteers
- Carers
- Support Groups/ Patient Advocates

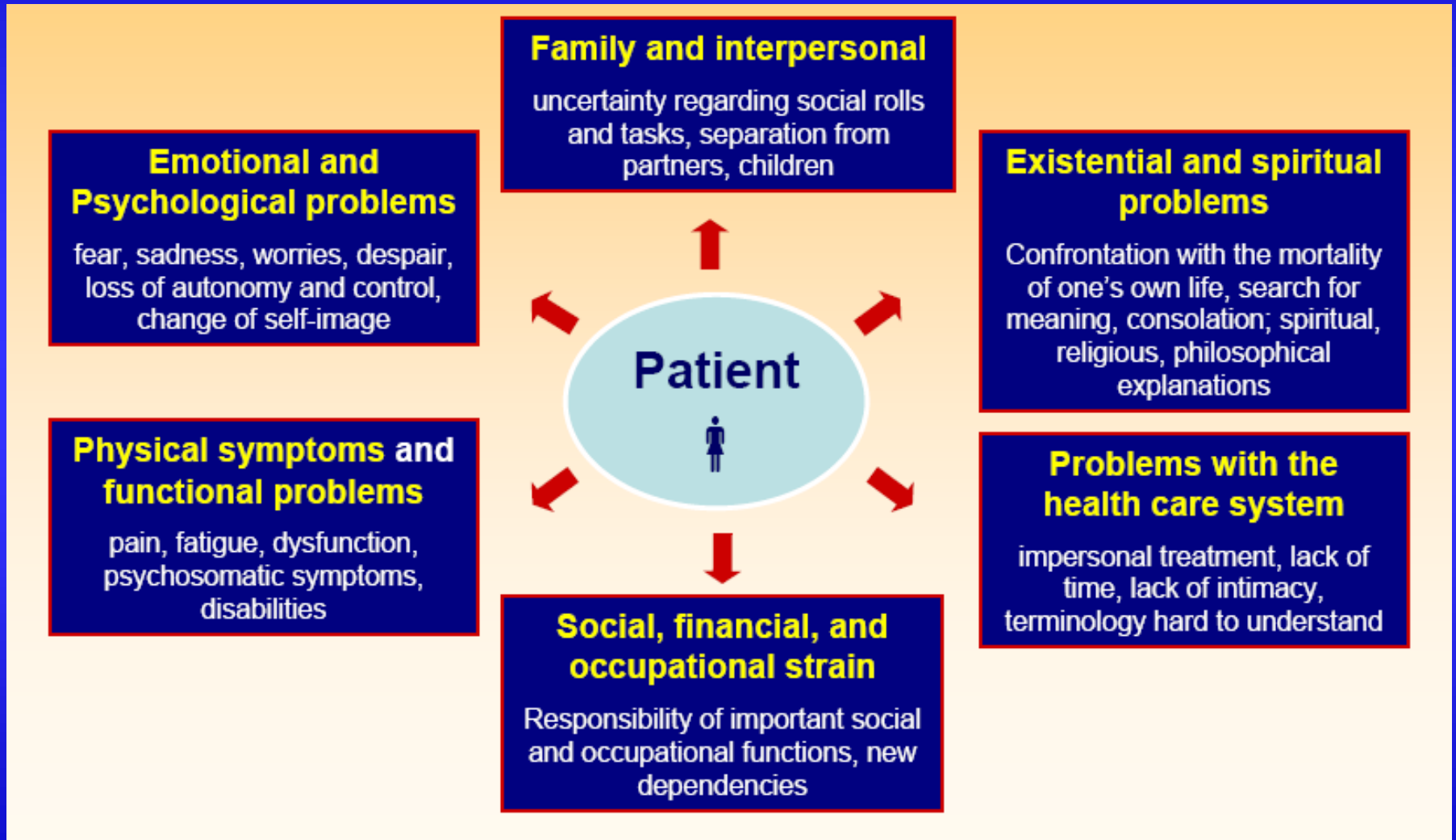
Why is Psycho-Oncology important?

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

Pathway of Cancer

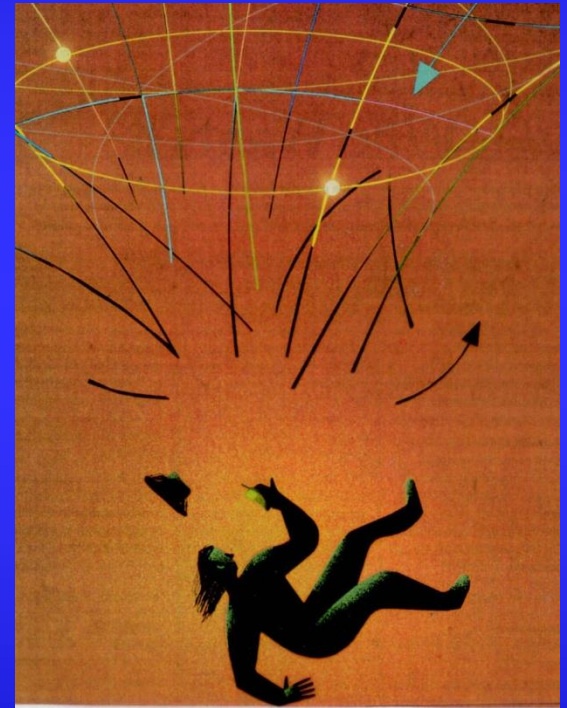


The impact of cancer diagnosis



Cancer is an existential threat and affects all areas of life in patients and their families:

- emotionally,
- in mind and
- behavior,
- in the daily routines ,
- in planning for the now and the future,
- In the view of the past feelings and insights about self and others



The psychosocial aspect of cancer

The facts:

- At least 50% of cancer patients suffer from stress-related symptoms or distress.
 - (Including anxiety, irritability and demoralisation.)
- Many develop more serious psychopathological conditions.
 - (Major depression or post-traumatic stress disorder)

Yet not all patients have access to Psycho-Oncological care

Symptoms during cancer treatment and course of illness

Most frequent symptoms and problems

	%
Fatigue	67
Mobility	58
Pain	55
Sleep disorders	55
Anxiety	52
Depressiveness	47
Tremor of hands and feet	38
Bowel problems	37
Cognitive problems	35
Nutrition problems	33

55% experience distress in relation with pain

52% experience high emotional distress.

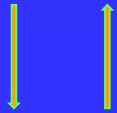
Fatigue, sleep disorders and depressiveness are strongest associated with high distress.

Distress in Cancer

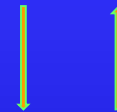
is an unpleasant emotional experience that could be psychological, social, spiritual in nature but which extends on a continuum from perfectly normal feelings of being vulnerable and sad and frightened, understandably, but that could go on the continuum to disabling problems such as depression, anxiety, panic, feeling isolated and being in an existential crisis.

Models of pathways to distress

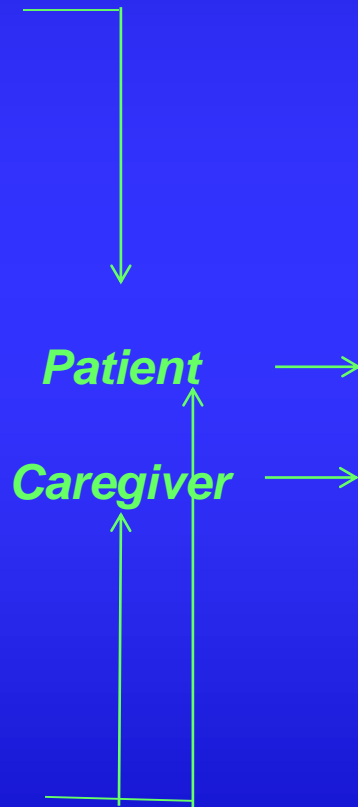
**Cancer and
treatment
related
stressors**



**Psychosocial
Stressors**



**Individual and
interpersonal
factors**



Continuum of distress

- Worry
- Anxiety
- Fear of death
- Demoralization
- Feelings of helplessness
- Feelings of regret, shame, guilt or anger
- Sadness
- Depression
- (Anticipatory) grief
- Loss of sense of dignity
- Desire for hastened death
- Loss of meaning and hope
- Mental disorders (e.g. adjustment disorder, Depression, Anxiety disorders)

Distress and Anxiety

- Many people experience cancer as the most dangerous illness in the world, independent of the improvements of medical treatment and the better chances being cured
- Sometimes patients are confronted by experiences with cancer of family members or friends, especially adverse disease process stays in the patients mind and influences the opinion of cancer
- Most of the patients never thought about having cancer previously/ before their illness
- A patient who had cancer before, knows the fear of recurrence. Even it is getting better in disease free time, a rest of uncertainty and fear will still remain.

Distress and Anxiety/Fear

Fear of progression

- A reactive behavioural »unconditioned« anxiety provoke from the experience of a real perception being diagnosed with a life threatening disease
- It means fear of recurrence/progression is a real anxiety, indicating an existential threat with the function, to facilitate power and motivation caring for oneself

(Waadt et al., 2011)

Distress and Anxiety/Fear

Fear of Progression

- uncorrectable concerns are dominating
- daily routine is controlled by these emotions and thoughts
- resulting in negative consequences with compliance disturbances

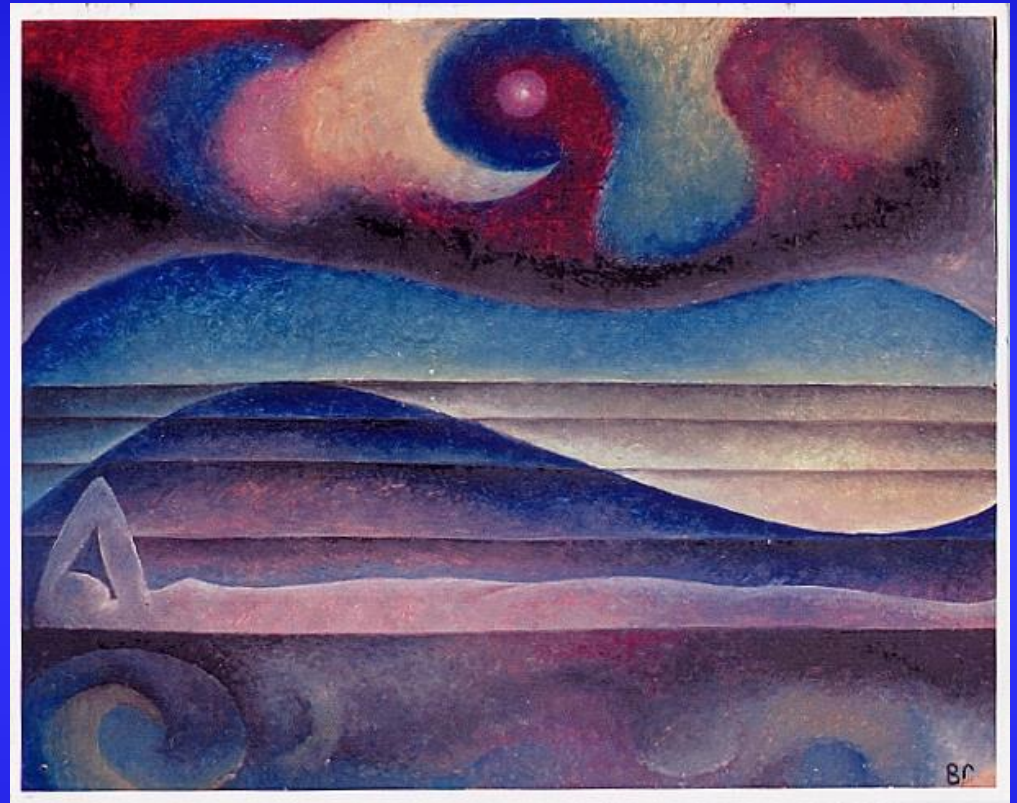
Distress and Anxiety/Fear

Loosing autonomy / being dependant in the context of advanced disease requires enourmous adaptation in relationships with significant others and can cause

- bond anxiety – being concerned about the availability of others -
- being anxious to have not the capacity taking care by oneself and loosing control
- development crises

Tan, Zimmerman und Rodin, 2005

„The focus on **fundamental questions of life and death** can lead us to some of the deepest **sources of anxiety and suffering** faced by patients.“



Kissane et al. (2009)

„Double Awareness“ Living with Paradox

*Facing the reality of the illness ...
and yet being engaged with life*

*engaging
in life...*



*while facing the
imminence of
death...*

Rodin & Zimmermann, J of the Am Academy of Psychoanalysis and Dynamic Psychiatry, 2008

„Double Awareness“ Living with Paradox

Existential challenges and handling the awareness of death challenge and ability

to accept the knowledge of nearby death...

...without giving up the sense of meaning in life and the will to live

„Patients have the ability to maintain two different psychological conditions: on one hand (dealing with death als alternative) the image of approaching death, on the other hand a feeling of hope and meaning in life.“

Psycho-Oncology services

Provide effective interventions for:

- preventing or reducing the distress and psychosocial morbidity associated with cancer
- improving patients' skills to cope with the demands of treatment and the uncertainty of the disease and improving their Quality of Life

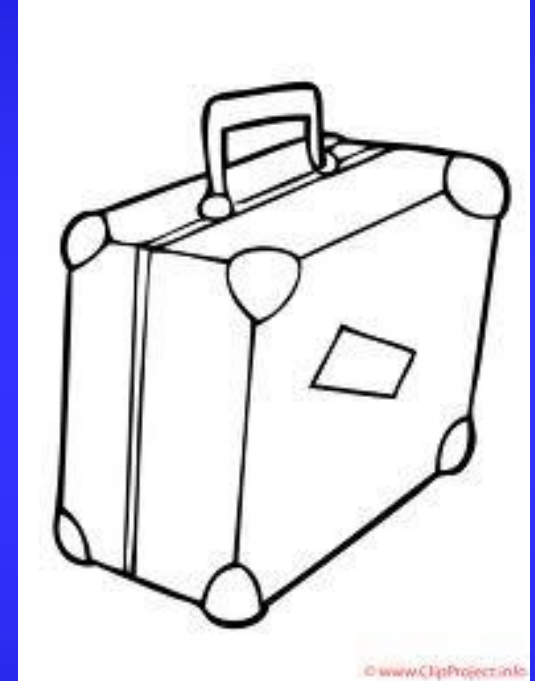
However these interventions and services are not yet regularly offered and included in routine clinical care to all human beings suffering from cancer...

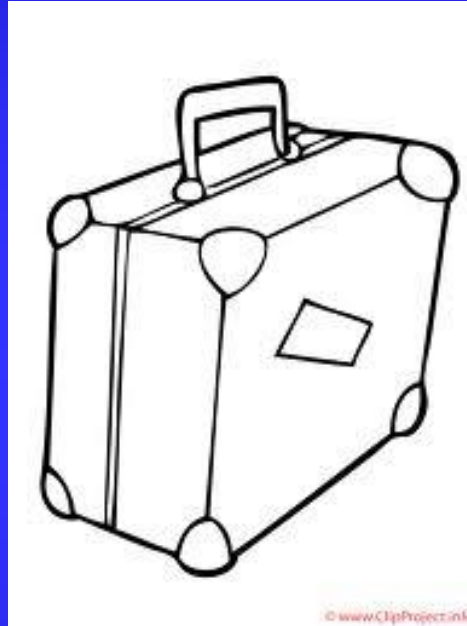
The Philosophy of Care

To enable Patients with cancer
to achieve maximum independence and quality
of life

To support their coping during and beyond the
disease and treatment

To encourage patients to develop self- help
skills for coping





?

Psycho-social Interventions

Basic Principles

- resource oriented approach (not deficit-oriented)
 - supportive attitude (strengthening / stabilization of the patient)
 - result-oriented dialogue
 - Patient- and need orientation (clarification of the assignment)
 - involving relatives – systemic point of view
- quality of life of health care providers (psychic hygiene)

Psycho-social Interventions

Basic principles:

- Bio-psycho-social Model of illness
- Supportive Psychotherapy
- Psycho-education, counselling
- Salutogenesis (protective factors, resources, resilience)
- Integrative, comprehensive concepts of different methods
- Model of disease consequences (ICF WHO)

Psycho-social Interventions

Specific approach in different stages of the disease
When?

- Clarification
- Communication of the diagnosis
- Medical therapy
- Aftercare
- Survivorship
- Recurrence / Metastasis
- Terminal stage of the disease

Psycho-social Interventions

What is a psycho-social intervention?

Basal psychosocial support includes all aids, which promote emotional and cognitive orientation. For patients in the initial phase of the tumor disease it facilitates the stepwise regaining of control, self-efficacy and prospects.

Psycho-social Interventions

For patients in palliative care situation the psycho-social support can maintaining hope and meaning, quality of life and promoting acceptance

Psycho-social Interventions

supportive expressive

solution-focused

mindfulness

narrative

cognitive behavioural

http://www.ipos-society.org/presentations/en/WatsonBultz_interv/player.html

Psycho-social Interventions

Emotional ups and downs

- Emotional ups and downs are a normal part of going through cancer and its treatment. There is no rule that says you have to be positive all the time. If you aim for this you may only feel a sense of failure, as it is hard for anyone to maintain a positive outlook no matter what.
- There is no evidence that failing to be positive all the time causes your cancer to come back. Scientific research does not back up this claim.

Remember: Nobody can be positive all the time

Psycho-social Interventions

Emotional ups and downs

- Not everyone wants to show their emotions.
- The need to express emotions also changes depending on the time, place and person.
- There is no rule that says expressing emotions or hiding emotions is either a good or bad thing.
- The yardstick is what makes you feel better.

Psycho-social Interventions

Emotional ups and downs

- Question: Do you need to talk about how you feel?
- Question: What happens when you talk about your emotions?
- Question: What do you want to talk about?
- Question: Who do you want to talk to?
- Question: Is something stopping you from talking?
- Question: What can you do?

Identifying Your Thoughts

Negative thoughts may be difficult to spot to start with – you are probably not always aware that you have them. However, you can learn how to become more aware of your thoughts using the following steps:

Also ask yourself: “How did I respond to the problem?”
“What did I do?”

Step 1 Learn to recognise those thoughts that make you feel low or worried

Step 2 Keep track of when they happen

Step 3 Consider how unrealistic or unhelpful they are to you

Also ask yourself: “How did I respond to the problem?” “What did I do?”

TIPS FOR IDENTIFYING NEGATIVE THOUGHTS

They tend to consist of lots of “I should....” and “I must....” statements. They are often over-generalisations i.e. if one thing is wrong everything is wrong

It may help to try the following:

Next time you feel anxious, worried, sad or low in mood:

STOP: Use strong emotions as a signal that you are facing a problem

EXAMINE: Become a detective and examine what triggered your feelings. Ask yourself, “Where am I?” “Who am I with?” “What am I doing?”

THINK: “What is going through my mind?” “What am I saying to myself about this situation?”

„Even if I knew that tomorrow the world would go to pieces, i wolud still plant my apple tree.“

Martin Luther (1483-1546)

„When we are no longer able to change a situation, we are challenged to change ourselves... „

„Those who have a `why` to live, can bear with almost any `how`“.

V. Frankl, Man's Search for Meaning

Exercise:

Diary of happiness

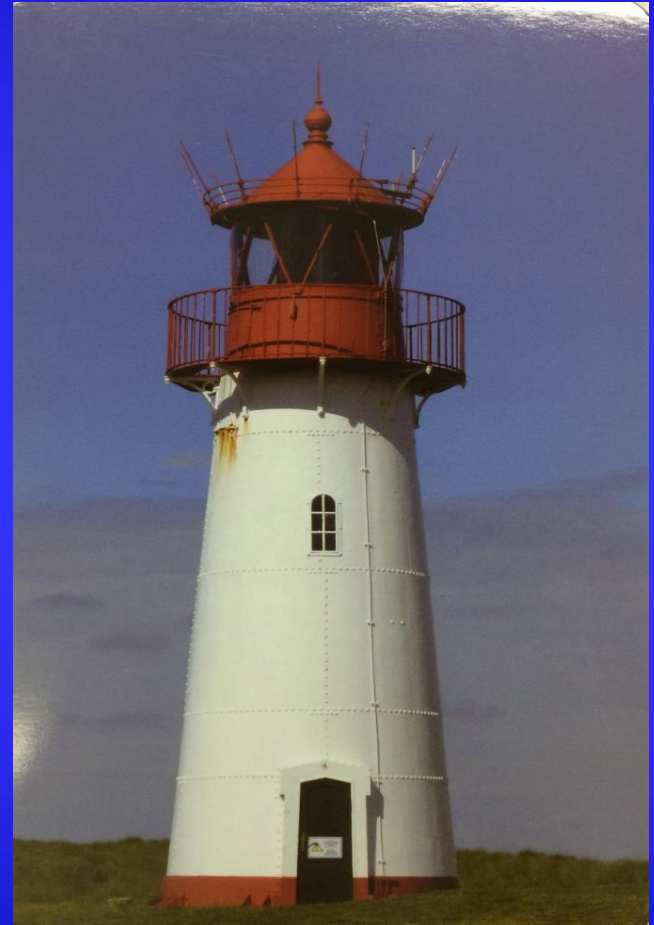
Reflecting at the end of the day

Write down 3 things which gave you a good feeling during the day and think about why these things you experienced as good

Sometimes it is helpful to read from your diary in front of others

What can I do ?

- What is the uniqueness of me ?
- What does life fulfill or what could it fulfill?
- How can I rediscover and use the uniqueness and strengths?
- How can my uniqueness and my strengths be helpful in this challenging situation?



What can I do ?

I am not the cancer – I have cancer

- To be free to create your life on your own
- To stay the captain or the leader of your life

What can I do ?

„Life as a chance“

Turning point does not
mean other things to do
but things to do
differently



Psycho-social Interventions

The goals are related to

- Physical level
- Cognitive-emotional level
- Practical level
- Social level
- Relationship / Family level
- Existential / Spiritual level

Psycho-social Interventions

Goals: Physical level

- alleviation of the consequences of illness and treatment (pain amongst others)
- rehabilitation: learn to cope with the consequences of the disease and disability
- supporting the improvement of physical functioning
- promotion of a healthy lifestyle (sports, nutrition, sleep): secondary and tertiary prevention
- regain strength

Psycho-social Interventions

Goals: Cognitive-emotional level

- Reduction of psychiatric comorbidity and psychological burden
- Learn, how to cope with fears and psychological strains
- Strengthening the self-value and the sense of dignity, despite the physical changes and the (increased) dependency on others
- Acceptance of own weakness and reduced independence

Psycho-social Interventions

Goals: Cognitive-emotional level

- To reveal new life perspectives, encouraging confidence, hope (finding of alternatives to hope for a cure) and bravery
- Mobilisation of inner resources (e.g. enjoyment skills)
- Retrospect to life: to appreciate the values and achievements
- Acceptance of change and grief, to let go

Psycho-social Interventions

Goals: Practical level

- Counselling concerning social issues (household, work, rehabilitation, retirement)
- Information about medical /nursing und psychosocial support (local, web-based)
- Information about self-help

Psycho-social Interventions

Goals: Social level

- Encouragement of motivation to actively participate in everyday life
- Return to work: handling the disease at the workplace
- Reduction of feelings of social exclusion and loneliness

Psycho-social Interventions

Goals: Relationship / Family level

- Strengthening of the harmony between patient and partner / family
- Clarification of the relationship between patient and partner / family
- Encouraging communication

Psycho-social Interventions

Goals: Relationship / Family level

- Dealing with intimacy, closeness and sexuality
- Handling sexual dysfunction
- Handling fertility disorder
- Support of parents, who have children with cancer
- Support of children, who have parents with cancer

Psycho-social Interventions

Goals: Existential / Spiritual level

- Integration of the experience of illness in subjective coherent contexts of life
- Openness for questions concerning the meaning of life, freedom, responsibility or religiousness
- Reflection / Encouragement of positive emotional states like love, joy of living, gratitude, sympathy, mindfulness
- Post-traumatic maturation (wisdom)

Benefits of psychosocial services

RCTs in Psycho-Oncology Interventions

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

Benefits of psychosocial services

Meaning based group-interventions

Intervention	Authors	Goals and results
Life-threatening Illness Supportive-Affective Group Experience (LTI-SAGE)	Ellison 1983	Reduction of emotional and spiritual burden, strengthening of hope and courage, strengthening of relationships
Supportiv-Expressive Group Therapy (SEGT)	Spiegel u. Spira 1991	Promotion of a supportive surrounding, strengthening of selfesteem, reduction of feeling isolated, discussion about death and dying
„The Healing Journey“	Cunningham u. Edmonds 1996	Support of coping strategies and reduction of distress promoting meditation and spirituality,

NICE clinical guidance on Supportive and palliative care

Key recommendations:

- There should be services to help people who live with the after-effects of cancer to manage these for themselves.
- People with advanced cancer should have access to a range of services to improve their quality of life.
- There should be support for people dying from cancer.
- The needs of family and other carers of people with cancer should be met.
- There should be a trained workforce to provide services.

NICE clinical guidance on Supportive and palliative care

Key recommendations:

- People affected by cancer should be involved in developing cancer services.
- There should be good communication, and people affected by cancer should be involved in decision-making.
- Information should be available free of charge.
- People affected by cancer should be offered a range of physical, emotional, spiritual and social support.

Further directions

Possibilities to work together with patients with gist

- Psychosocial care has to be an essential requirement for quality of care
- Support groups should be connected with national associations of psycho-oncology or local with psychooncologists
- Common seminars (psycho-educative programs, communication skill training, empowerment)
- Creating together tools to provide for new diagnosed patients with gist to get support to cope with the disease

Thank YOU!

Danke!



