

Psychosocial Aspects of Palliative Care

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Topics of the presentation:

- I. Psychological aspects and treatment options*
- II. Communication – Doctor – patient relationship*
- III. Education of professionals*
- IV. Public issues – education on death and dying*

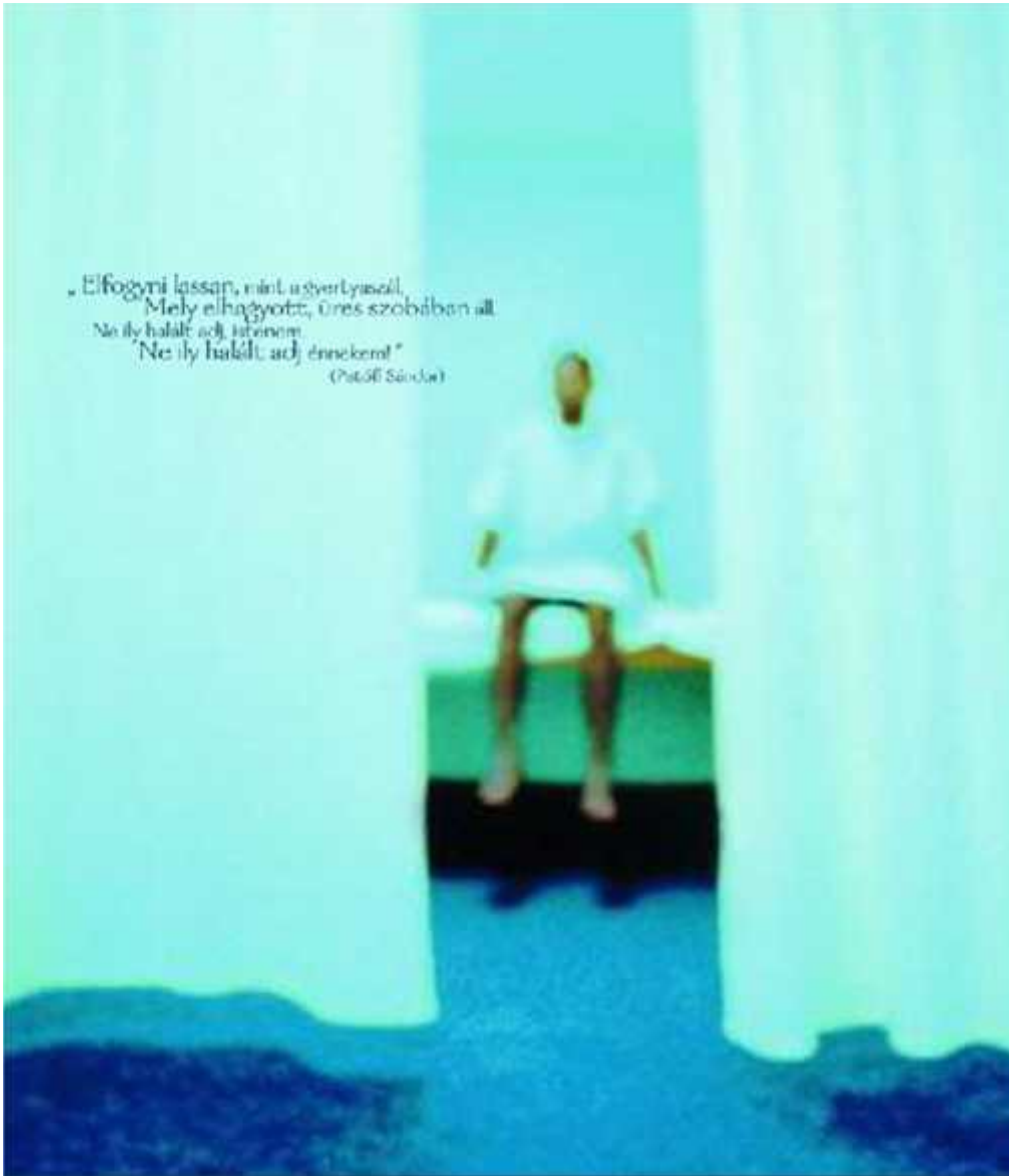
I. Psychosocial Aspects of Palliative Care

Psychological approach to cancer

- Cancer is equal with death and dying
- Fear of suffering, pain and other symptoms
- Anxiety, depression
- Suicidal thoughts
- Fear of loneliness and isolation
- Fear of the loss of beloved ones

Terminally ill patients mainly die in hospitals

- lonely
- depressed
- suffering of pain
and other symptoms




„Elfogyri lassan, mint a gyertyasál,
Mely elhagyott, üres szobában áll.
Ne ily halált adj jónemem,
Ne ily halált adj énekeim!”
(Petőfi Sándor)

Ha családjában van olyan súlyos beteg, akinek neménytelen állapotán már csak az otthon befogadói szeretete enyhítése, gondozása a Hospice Otthonápolási programmal. Orvosaink, szakképzett ápolónk, valamint önkéntesek hűhöz jönnek, és minden megtesznek azért, hogy a beteg múltbajaira derítve éhizzen egészen az utolsó perig.

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BetVonal: 05 90 204004
Ingenyen hívható telefonos lelki segély szolgálat: nikibetegek és hozzátartozók számára.

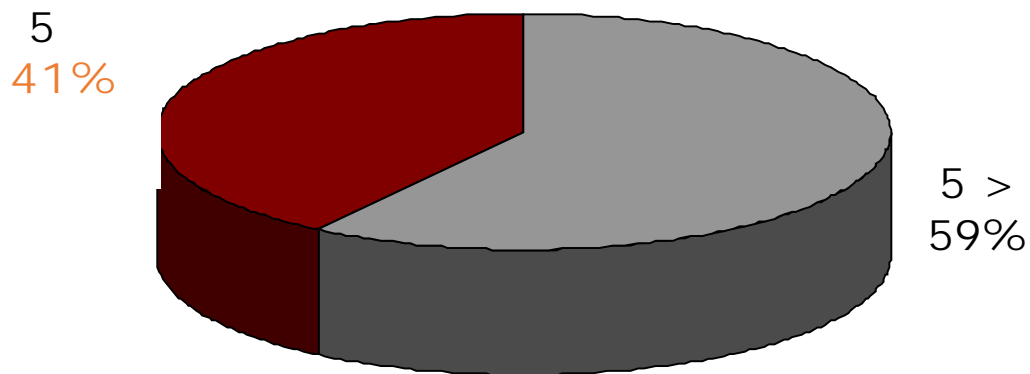


Psychological aspects of PC - - general principles I.

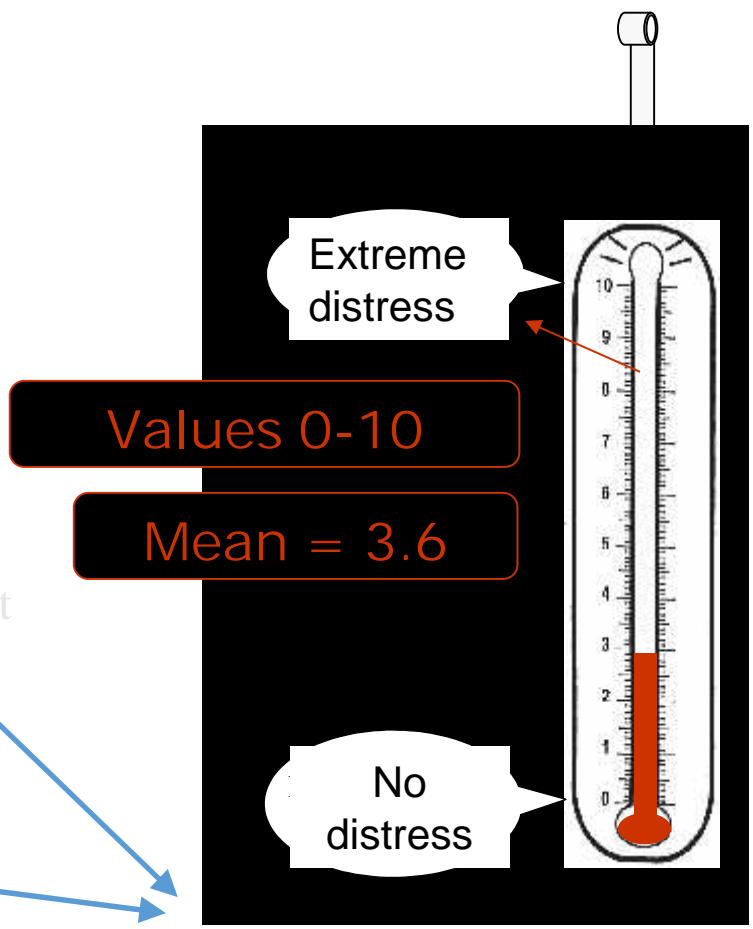
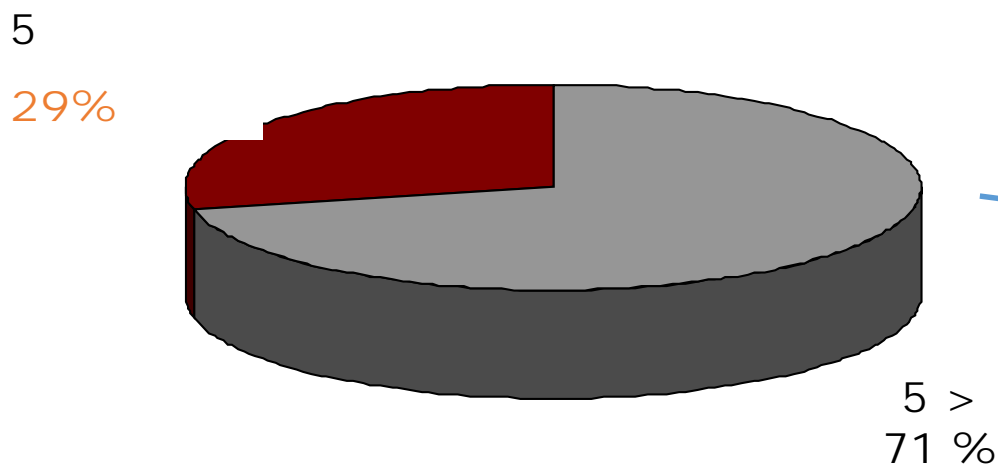
1. Psychological distress is commonly experienced in cancer and palliative care
2. Prevalence of anxiety and depression are significantly higher in cancer (10-30%) and even *higher in PC patients* (45-56%) (Meyer et al, 2003)

Psychological status of Hungarian cancer patients: Distress Thermometer (Sample: 924 cancer patients)

5 points and above: 41%



Psychological state of American cancer patients (Roth et al., 1998)

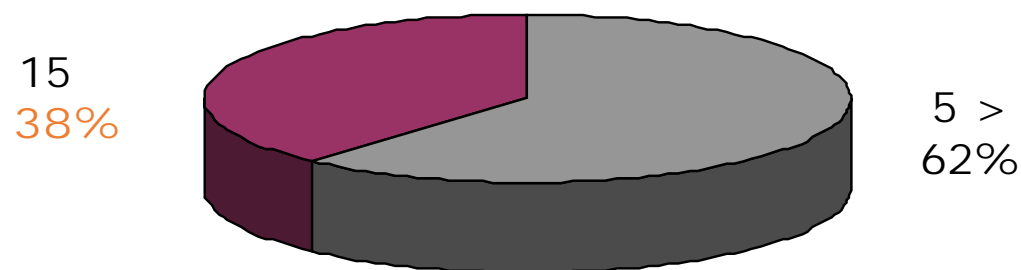


Khi (p < 0.0001)

Comparison of HADS values (No: 924 cancer patients)

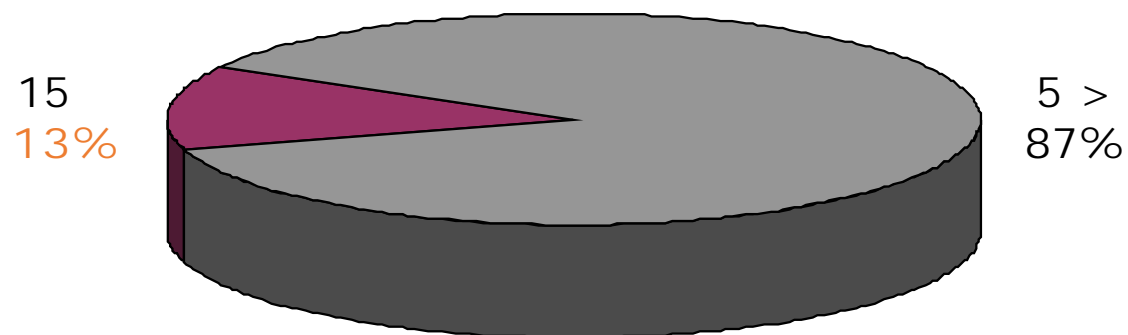
- HADS points of Hungarian cancer patients

38% of them is above 15 points



- HADS points of American cancer patients

(Roth et al., 1998)

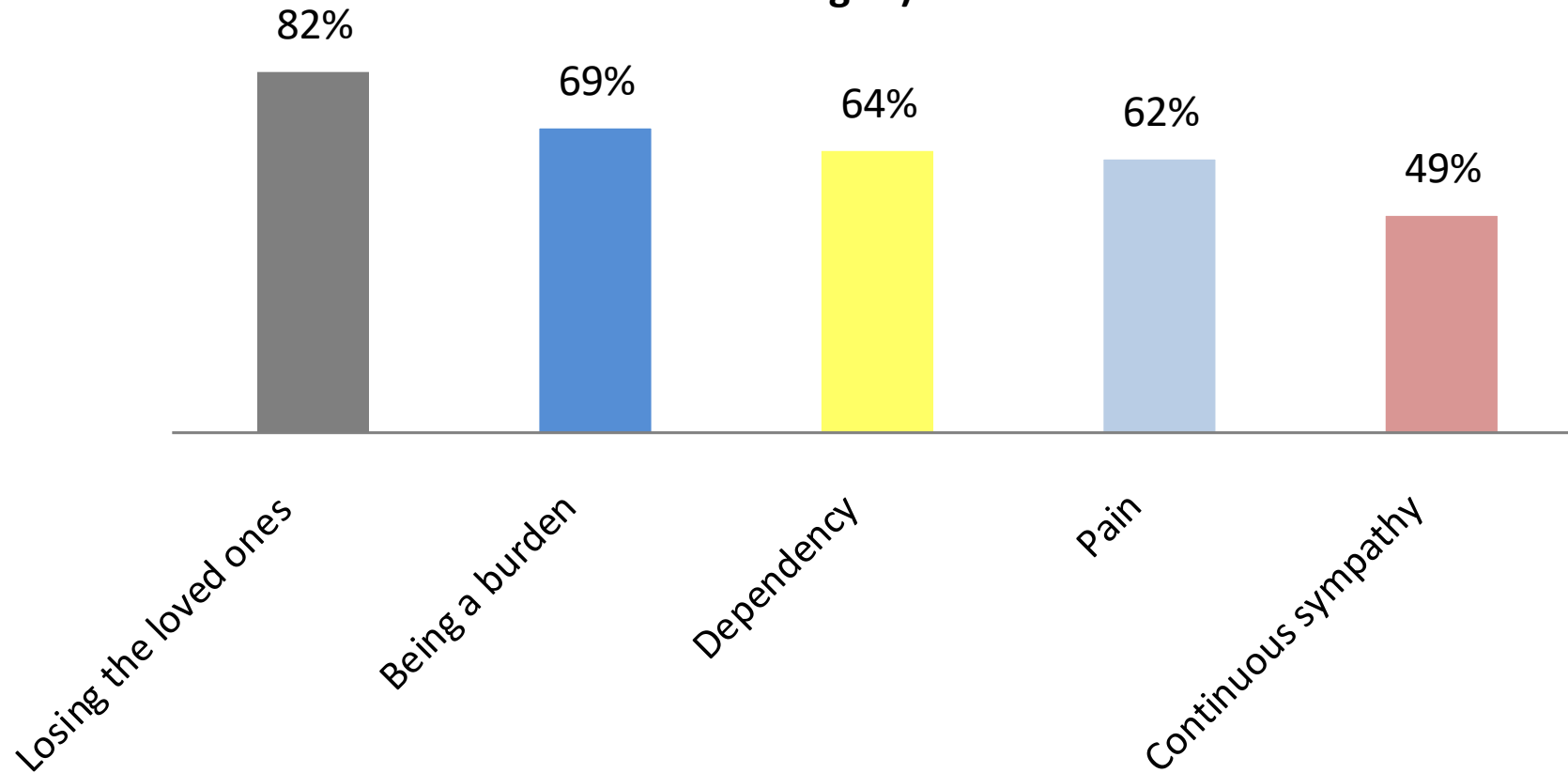


P = 0.0001

Psychological aspects of PC - - general principles II.

3. Psychological distress has a significant impact on QoL, on degree of pain, on physical functioning and on the life of families (Thekkumpurath et al. 2008)
4. At least 10-15% of patients need special psychological or psychiatric intervention (Payne et al. 2002)

What are you most scared of in connection with an incurable illness? (answers stating *Scared* and *Very scared* have been merged)



Opinion poll study on 1000 Hungarian inhabitants

Psychological aspects of PC - - general principles III.

5. However there are various services available to assist patients experiencing psychological distress, currently there remains a lack of integration of specialized psychological support services in PC

(Price et al. found that 45% of UK hospices had no access to psychologist (2006))

Social issues in PC

Illness impacts the whole family

- Role in the family
- Relationships, friends, community
- Isolation, abandonment
- Financial recourses, expensis

Spiritual issues in PC

Spiritual issues vary from region to region regarding:

- Cultural issues
- Meaning, value
- Existential, transcendental
- Rituals, symbols,

Psychosocial Priorities of WHO National Cancer Control Program

- to reduce distress in cancer patient at all stages of illness, and their families, including bereavement
- to develop national minimum standards for psychosocial care
- to assure that psychosocial care is integrated into the overall medical care
- to provide education on psychological aspects

Complex Treatment of Anxiety and depression is based on

- Multimodal treatment
- Useful methods:
 - *pharmacotherapy (antidepressants, anxiolytics, etc.)*
 - *Psychotherapy (different techniques)*
- Additionally honest and equal relationship between physician and patient helps reduce anxiety

Psychological Counselling

- Wide range of methods from verbal to non-verbal techniques for individuals or groups
- Efficacy proven in numerous studies
- Short-term interventions may be effective in early phase of symptoms
- Flexibility is required, patient's somatic state must be considered

Psychological support for the family



Music therapy at home



Psychiatrist in the Hospice House (B. Breitbart)



Effectiveness of psychotherapy in palliative care

32 randomized study (Jessica J. et al. 2018)

Psychotherapy reduced

- Depression - *large effect*
- Anxiety - *small effect*
- QoL - *small effect*

Significant moderators of intervention effects:

- Type of intervention and provider (*larger effect of C-B, mindfulness, dignity therapy, and given by specialist*)
- Number of sessions (*longer – large effect*)
- Sample of age (*younger – large effect*)

Barriers to treatment depression

1. Mistaken beliefs that depression is an inevitable consequence of terminal illness (Lawrie, 2004)
2. Symptoms of depression are not/late recognized
3. Antidepressants are prescribed too late, often within the last 2 weeks of life (Lloyd-Williams et al.1999)

Psychosocial Support and program for ???

Psychological support

for patients and their families

Supporting the

bereaved family members

Burn out prevention for

the medical staff

Supervision of the

psycho-oncology staff

End of life care, death management

Patient's mind is full of thoughts of:

- Life closure (completing business, closing relationships, saying good-bye)
- Giving gift (things, thoughts)
- Legacy creation
- Preparation for expected death
- Funerals, memorial services



End of life Planning Foundation 2014

Established by volunteers of Hungarian Hospice Foundation

- Infos, documents
 - about topics of end of life decisions:
 - healthcare wishes – i.e.: living will
 - financial planning
 - questions of spirituality
 - digital legacy
- Participating in policy making
- Ostrich Cafés – Get out your head of the sand







II. Communication – Doctor – patient relationship

Communication – Doctor-patient relationship

- Most of Eastern-European societies were not opened for honest communication
- Health care system is a hierarchic one. Who's responsibility is breaking bad news?
- Doctor – patient relationship is more paternalistic than partnership

Why is so difficult the open communication in health care?

- Bad news is information may *unpleasantly alter* patient's view of her future.
- Bad news usually *causes distress* to both the patient and the news-giver. Be prepared for a strong emotional reaction (tears, anger).
- However doctor-patient relationship should be based on trust.

Why is so difficult the open communication in health care?

- Education on communication is *missing* in the medical curricula
- Physicians are *afraid* of telling the truth
- Patients are often *reluctant* to confront with difficult problems

Studies about Need for open communication in the end of life

EVANS et al (2012)

- 30 interviews with *patients*, in regard to communication style, they *agreed that physician should*
 - be open,
 - give clear explanations
 - avoid jargon,
 - check understanding

Studies about the role of spirituality in end-of life communication

TANG et al (2016)

- **325** cancer patients was followed until death
- participants who knew and highly accepted their prognosis were significantly less likely to experience severe anxiety symptoms

Studies about the role of spirituality in end-of life communication

LAI et al (2017)

- **399** hospice patients, enrolled in a central Italian hospice center
- in terminally ill patients with cancer, the levels of depression and anxiety were lower in patients aware of their own illness state
- involving spirituality in care process helped the patients to be aware of their illness state

The consequences of insufficient communication

WALLIN et al (2018)

- nationwide questionnaire study in Sweden of 174 individuals who had lost a sibling to cancer
- who were *not satisfied* with communication were *more likely to report anxiety (26%)* than those who were satisfied (**11%**)

Special program on communication, doctor – patient relationship in Hungary

- 18 month program of Hungarian Hospice Foundation
- Aim: to improve doctor – patient relationship
- Collaboration with medical institutes
- 6 month collaboration with the Art and Design University, involving art to improve doctor-patient communication



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PARTNERSHIP / PARTNERKÉNT



WITH EMPATHY /

EGYÜTTÉRZŐEN

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RELATIONSHIP

Public Installation



How did you live before?

How do you live now?

How would you like to live?

How would you like to die?



Hospice assist handle

Results of the project

- 2 booklets were issued on communication
- It was disseminated to hospitals, medical centers, oncology wards. GPs
- In a Scientific Medical Journal there was a special edition on this subject
- Several presentations

III.

Education of professionals

National Education Programs

- Medical personnel
- Courses for nurses, physicians, psychologists, physiotherapists, etc
- Students from different fields, eg. theology, sociology,
- Burn-out training

Education of lay people

- Volunteer education, (yearly 80-100 persons)
- Training for journalists on topics: loss, death and dying, hospice care
(8-12 participants / course)
- Training of teachers – for Daffodil schools participants

Journalists





Training for teachers



Budapest: Eastern-European Training and Resource Center 2003 - 2015

- Regular courses and placement with the participation of Post-Sovjet-, and other countries from Eastern-European region
- 23 countries, recently also placement
- Teachers from Oxford led by R. Twycross, Poland, led by J.Lucak, and other centers
- PC policy conferences, organized by OSI

Palliative care course , 2003. Budapest

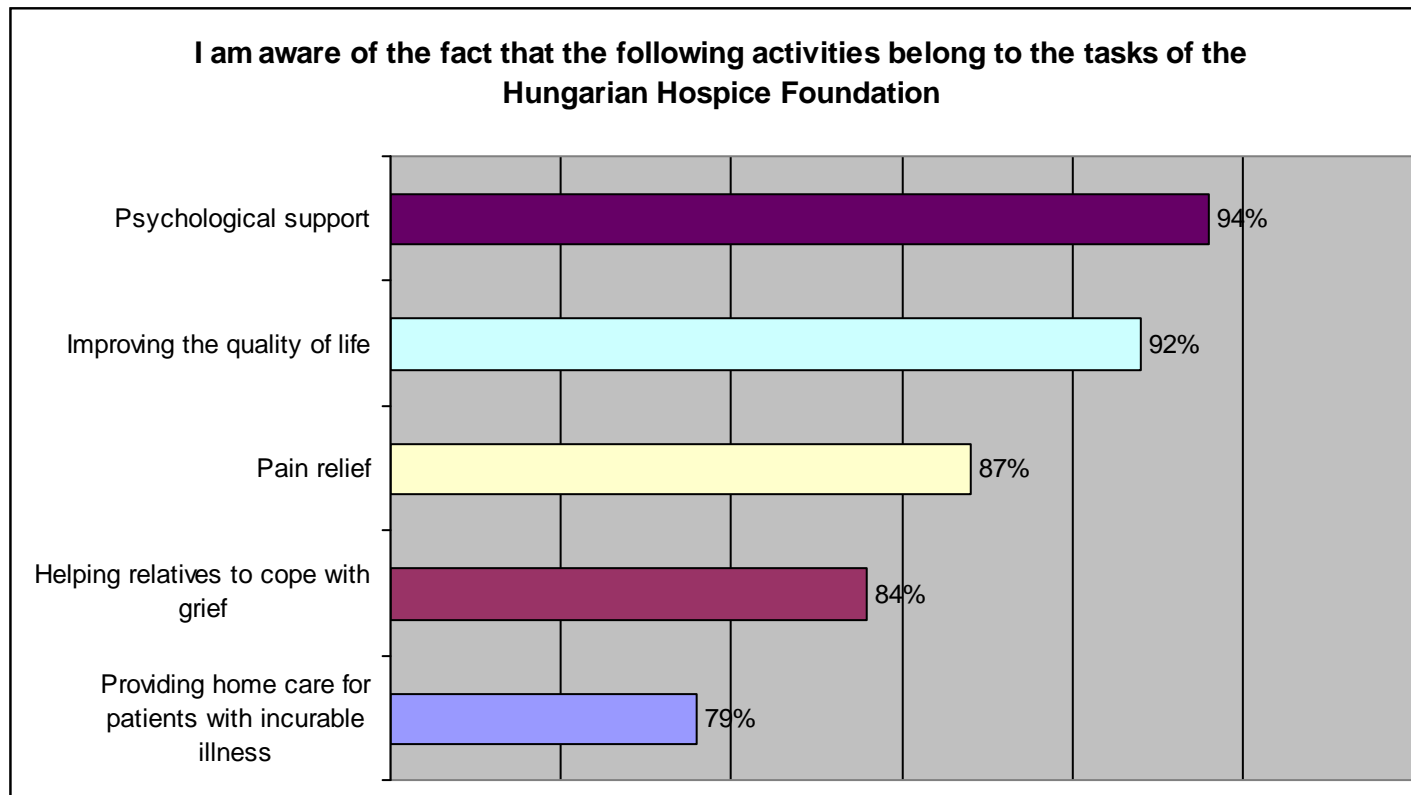




IV. Public issues – education on death and dying

Expectation of public about end of life care

(Sample: 1000 persons)



Elements of Public education

1. Publicity campagne
2. New media
3. Fields of hope
4. Sport „ambassadors”

1. Publicity campaign for change attitudes

Aims

- To raise awareness of hospice-palliative care
- To promote the integration of hospice-palliative care into national health service
- To draw the attention of policy makers on suffering, dying patients

Elements of publicity campaign

- Spots in different TV channels
- Adverts in printed and online media
- Billboards across Budapest
- Indoor adverts
- Press conference
- Interviews about our activities



Két karodban nem ijeszt majd
a halál nagy
szonora sem.
Két karodban a halálon,
mint egy almon
át esem.

[Radóti Miklós]

Kérjük, hogy adójának 1%-át ajánlja fel a menthetetlen rákos betegek ápolására!

Adószám: 19663258-1-43. www.hospicehaz.hu



BILLBOARD

2. New Media communication

- Since 2010 social media, as Facebook, since 2017 Instagram are modern way of communication about death and dying, news about hospice care, etc
- Video spots about hospice have been marketed with free video sharing websites like Youtube

3. Fields of hope project

Aims

- to teach children on death and dying, and on solidarity
- to draw public attention on dignity of life
- to raise money for hospice activities

Fields of hope project







4. Sport - “ambassadors”

Since 2014 charity runners are taking part in Hungarian or international races wearing the daffodil pins, and yellow T-shirts to raise awareness for hospice care

In 2019 the Hungarian winner (in both category of men and women) on **Spartathlon** race (246 km) in Greece wore Daffodil and represented the Hungarian Hospice Foundation





Conclusions

- Cancer, death and dying still belong to taboos in Eastern – European region
- Advanced cancer, incurability causes fears, distress and depression
- Early recognition and treatment of psychological symptoms is crucial.
- Education of professionals and public has a great importance

GOLD



Thank you for
your attention