Psychosocial Support in Palliative Care

For CHO/SN

LEARNING OBJECTIVES

- Explain the psychological and spiritual issues related to palliative care and in patients with chronic illnesses
- Recognize the psychosocial and spiritual needs of patients and caregivers
- Develop empathic listening skills, identify and respond to emotional and spiritual distress when it occurs

CASE STUDY

During home care, you visited the house of Kannan, a 33-year-old manual laborer, who had a fall from a height, causing permanent damage to the spinal cord. Both of his legs are paralyzed and is on a catheter to pass urine. He has two children, aged 8 and 4. His wife is also neither equipped nor trained to earn money.

Discuss how his present physical condition is going to affect his life and his family's life. Discuss possible issues related to a) Finance b) Personal relationships c) Social activities d) Health and social care: accessibility and quality e) Work/capacity to work and f) Sexuality

How can you help him?

Palliative care is an approach that improves the quality of life of patients and their families, facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.- WHO

WHY PSYCHOSOCIAL CARE?

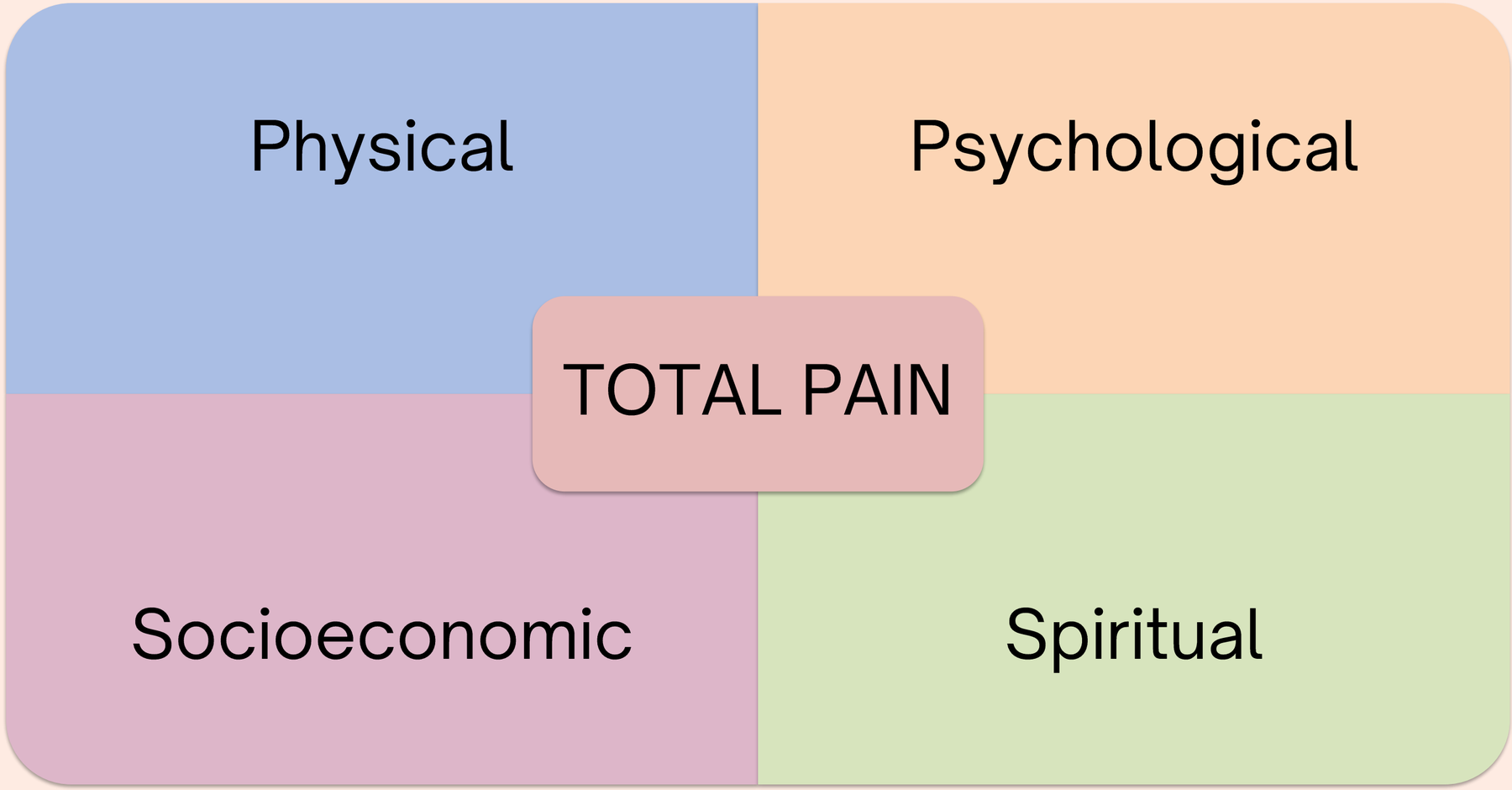
- Living with a life-limiting or life-threatening illness, or the awareness of approaching death causes unique stressors and challenges.

- Understanding the factors related to a patient's quality of life is essential in providing appropriate care.

“TOTAL PAIN”

When a patient reports his/ her subjective pain on the pain scale, it is important to remember that the physical pain reported by a patient is compounded by his/ her current life circumstances

ILLNESS RELATED SUFFERING IS MUCH MORE THAN JUST PHYSICAL DISTRESS



CASE STUDY

During the visit by HWC team, it was observed that Ms. Savitri 52 year old lady, living with her unmarried 26 year daughter who is breadwinner for the family, diagnosed with breast cancer (stage IV) was very anxious and distressed, and cannot sleep. She is undergoing chemo/radiotherapy on monthly basis. She has a lot of back pain and has been vomiting every day. She was crying repeatedly while talking. She asked the CHO/S/N why she developed this condition, what evil she has done in her life, why only she has to suffer this much. She also expressed worries about her daughter, who had to give up her job to look after her. Her younger son is waiting to get into college.

List out the different examples of suffering as per the Total pain model?

CASE STUDY:

Assessment along all parameters revealed

Physical

Pain

Vomiting problems

Inability to sleep

Psycho-social

Concerns about children

Isolation from neighbours

No support from relatives

TOTAL PAIN

Socio-economic

Cost of treatment

Loss of daughter's job due to mother's illness

Son's education

Spiritual

Loss of hope

Despair

Loss of connection

POSSIBLE PSYCHOLOGICAL IMPACT OF ILLNESS

- Anger (Why me?)
- Fear (What will happen to me?)
- Loss (I have lost everything that gave my life value)
- Guilt/Blame (I should have gone earlier to the doctor/I did not have the money to see a proper doctor)
- Shame (How will people now treat me and my family?)
- Grief/Despair (This will only get worse and end in suffering and death)
- Hope (I shall remain pain free and continue to function independently)

COMMON CAUSES OF FEAR & ANXIETY

- Feeling of uncertainty- of diagnosis, treatment, prognosis, and time of death.
- Isolation and separation following death.
- Claustrophobia- patients may feel claustrophobic about being confined and buried in a coffin
- Abandonment–by caregivers or health care team
- Pain/suffering -Anxiety and fear that the pain would worsen and suffering might increase.

CONTD...

- Knowledge of advanced/ progressive disease
- Death....more so, it is the fear of the process of dying and fear of the unknown
- Family- future of the family
- Of treatment- e.g. pain during procedure etc., the outcome of treatment and side effects
- Leaving unfinished business-e.g. children to be educated or married, property and financial matters to be settled, reconciliation, pardon and forgiveness.

PSYCHOSOCIAL SUPPORT

- Do not consider the patient's problems as insignificant.
- Listen attentively. Be a good listener.
- Do not force your opinions/beliefs upon the patient.
- Do not ignore the patient's queries.
- Try to address the social issues that can be addressed.
- Do not give any false hopes.
- Ensure confidentiality.
- Do not force the patient to talk.

PSYCHOLOGICAL DISTRESS

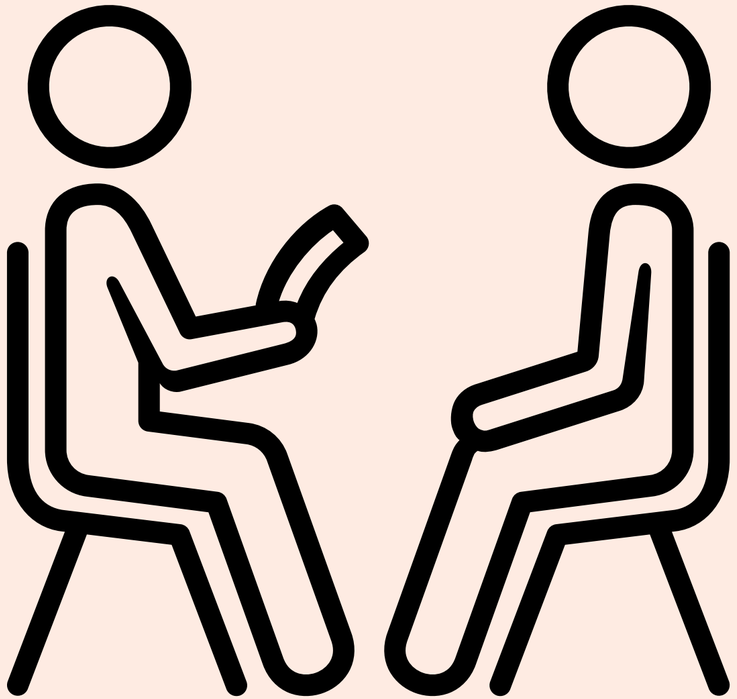
- Some psychological distress will occur with any life-limiting illness.
- The ability to recognize and relieve this is an essential skill in palliative care.

FACTORS PREDISPOSING PSYCHOLOGICAL DISTRESS

- THE DISEASE
- UNSURE ABOUT DISEASE, TREATMENT
- UNCONTROLLED/POORLY CONTROLLED SYMPTOMS
- TREATMENT TEAM
- SOCIAL
- CULTURAL
- SPIRITUAL

IT IS ABOUT PAIN

- Better pain control and symptom control methods need to be tried out.
- Pain can be the root cause of most psychological issues.
- Also, untreated depression or anxiety may worsen the pain.
- Good pain management with available opioids may help in improving their coping skills, along with other symptom management.



Exploring and acknowledging concerns

Effective counselling

Psychological intervention

EARLY DETECTION AND TREATMENT OF PSYCHIATRIC MORBIDITY CAN INFLUENCE

OUTCOMES	TREATMENT	CARE
• good psychological outcome • mood / affective state • coping style • treatment compliance • quality of life	• Counselling and education • psychotherapy • psychotropic medications	• Support for the family • helping the patient / family come to terms • communicating well • maintaining hope in a realistic way • setting realistic goals • scheduling activities • communicating and interacting with the patient creating an atmosphere in which the threat of dying and death may be freely expressed

SOME PREVENTIVE MEASURES

- Counselling and education from the time of diagnosis.
- Supportive care through the diagnosis, treatment, failure of treatment, recurrence of the disease, progression of the disease and the terminal stage could help the patient and family glide through smoothly from the curative treatment to palliative care.
- Increased acceptance by family members and patients

DENIAL

- Denial in a palliative or acute setting is a complex process
- May involve an unsteady process in coming to terms with a frightening prognosis.
- Denial is the most frequently seen coping mechanism
- Denial may result in the patient behaving differently with different people—close relatives they may appear to know nothing of the illness or its seriousness but can discuss it openly with another relative or a professional care giver

ROLE OF CHO AND STAFF NURSE - DENIAL

- **treat underlying causative factors** before rushing to prescribe anxiolytics or antidepressants
- **general measures** -a caring, considerate, unhurried, non-judgemental approach
- good **listening**, good **communication**
- **reassurance** about continuing care
- **respect** for the person and individuality - allow discussion of fears regarding future suffering, life expectancy because even patients ‘in denial’ appreciate such discussions

SPIRITUAL WELL-BEING

- Interconnectedness with the world
- Meaning / Purpose
- Strength and Comfort
- Hope

<u>Remember:</u>
Spirituality is often related to belief in God or religion.
<u>BUT</u>
Not necessarily related to God or religion.

Before tackling spiritual issues:

- Ensure physical symptoms are controlled
- Convey that you care
- Establish rapport
- Concurrently handle psychosocial issues

SPIRITUAL ISSUES

- Assess history of religious affiliation, spiritual beliefs, spiritual meaning of illness and death.
    - “Do you wonder regarding the meaning of your illness?”
    - “How does the current situation affect your relationship with God, your beliefs, or other sources of strength?”
    - “Does your illness and grief interfere with expressing your spiritual beliefs?”






SPIRITUAL ISSUES

- Assess whether patients need help with unfinished business.
- Provide understanding and acceptance.
- Support crying by offering a caring touch.
- Encourage verbalization of feelings of anger or loneliness.
- When requested by the patient, arrange for priest, rituals, music, prayers, scriptures or images.
- If requested, sit with the patient who wishes to pray, and arrange for a priest at the time of death as requested by the patient.
- Do not provide intellectual solutions for spiritual problems.

SEXUALITY ISSUES

- Make sure that the patient gets the time and privacy to spend time with the partner.

- Encourage the patient to open up on his/her problems and needs.

- In the case of patients with diseases that are transmitted sexually (AIDS/hepatitis) allow them to discuss with the doctor about safe methods of sexual intercourse






Provide information as & when needed

Spend adequate time with patient & family

Listen for feelings behind words. Non verbal cues

Encourage & reassure while maintaining realistic hope

Empathetic communication

COMPONENTS

Being accessible – where you can be reached and when

Observe Surroundings in patients home

Keep appointments

Maintain confidentiality

SUMMARY NOTES

- Palliative Care is incomplete unless we address psychosocial and spiritual issues of patients and their caregivers.
- Empathic listening is vital, and is about:
    1. Relationship building
    2. Observation of the patient and family
    3. Identification of the psychosocial & spiritual issues through effective communication
    4. Formulation of goals
    5. Assessment and evaluation
    6. Regular follow-ups
- Referral should be done wherever needed
- Should be conscious while communicating and should know our limit (never to give false hope)

Thank You