GIVINGCARE
Empowering Caregivers

A2.2 – Educative resources for teachers

Module: End of Life Care

Sub-Module: **General Principles of Symptom Control**

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Lesson Outcomes

- Identifying common symptoms in situations of end of life
- Developing relationship skills with user and caregiver as part of symptom control
- Understanding the aspects of work in inter and trans disciplinary team in palliative care and the specific role of the caregiver

Topics

1. Observation, evaluation, and control of common symptoms in situations of end of life
2. Comfort measures in the final stage of life.
3. Education of user, caregivers and families/important others
4. Care in agonizing phase
5. Work in inter and trans disciplinary team in palliative care
6. Selfcare of professionals

Introduction

Current literature emphasizes that too many people experience important suffering during their illness trajectory.

Human suffering improves inability to enjoy remaining life:

- Simple tasks become a challenge
- Isolation from loved ones
- Unable to fulfill remaining life goals
- Worst fears about dying become realized
- Destruction of hope for any quality of life
- Loss of meaning
- Spiritual distress

Observation, evaluation, and control of common symptoms in situations of end of life

SYMPTOM MANAGEMENT

NEEDS

The Patients’ View:

FIVE Components of Quality End-of-Life Care

1) Symptom management

2) Avoid inappropriate prolongation of dying

3) Improve sense of control

4) Burden Relief

5) Strengthening relationships with loved ones

Perception of Symptoms (particularly at EoL)

- Perception of **symptoms are worsened** by anxiety, fatigue, emotional and psychological/ spiritual distress
- Presence of a psychological component **does NOT mean** distress should be ignored

Exploring and alleviating contributing sources of stress will help to:

1. Control symptoms
2. Lead to better decision-making
3. Improve Quality of Life/ Quality of care

Three General Rules in Symptom Management

1. Any symptom is a source of distress/ suffering to an individual person (as that person claims it to be)

2. All treatments (risks, benefits, options) need to be discussed within the context of the person's values, culture, goals and fears

3. When illness is advanced and death very near**, the exact causes of any given condition** are not relevant (investigations may be inappropriate during this time)

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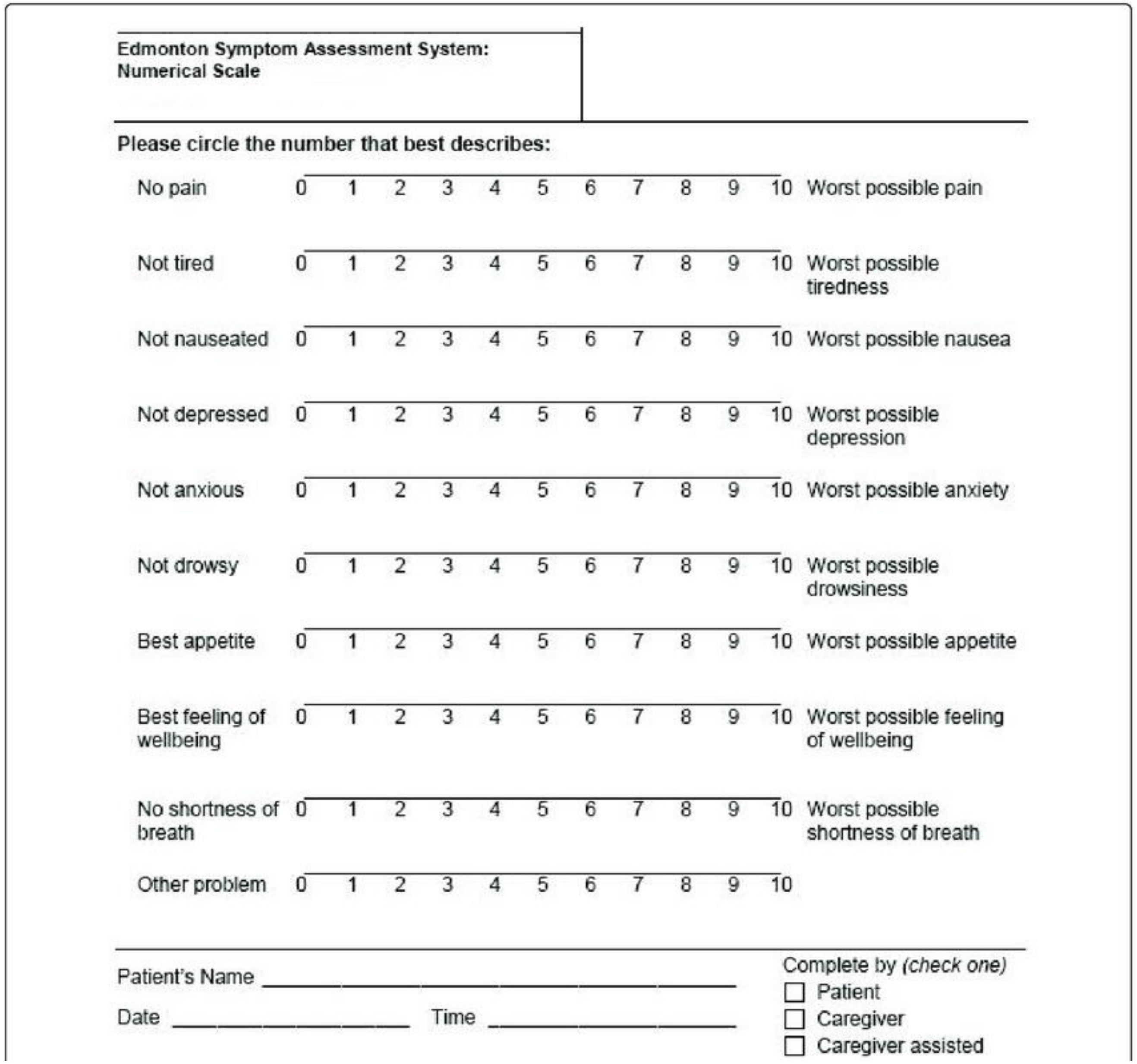
Approach to Symptom Management

- Multi-transdisciplinary team approach
- Around the clock” medication for continuous symptoms

- Symptom assessment/ **EVALUATION**
  - Rating symptoms on a scale (ESAS/PPS/KPS)/ **EVALUATION**
  - Frequent re-assessments/ **EVALUATION**
- PC consult if uncertain, not responding or difficult to control

Some tools available to symptom assessment:

1. Edmonton Symptom Assessment Scale



**Edmonton Symptom Assessment System:
Numerical Scale**

Please circle the number that best describes:

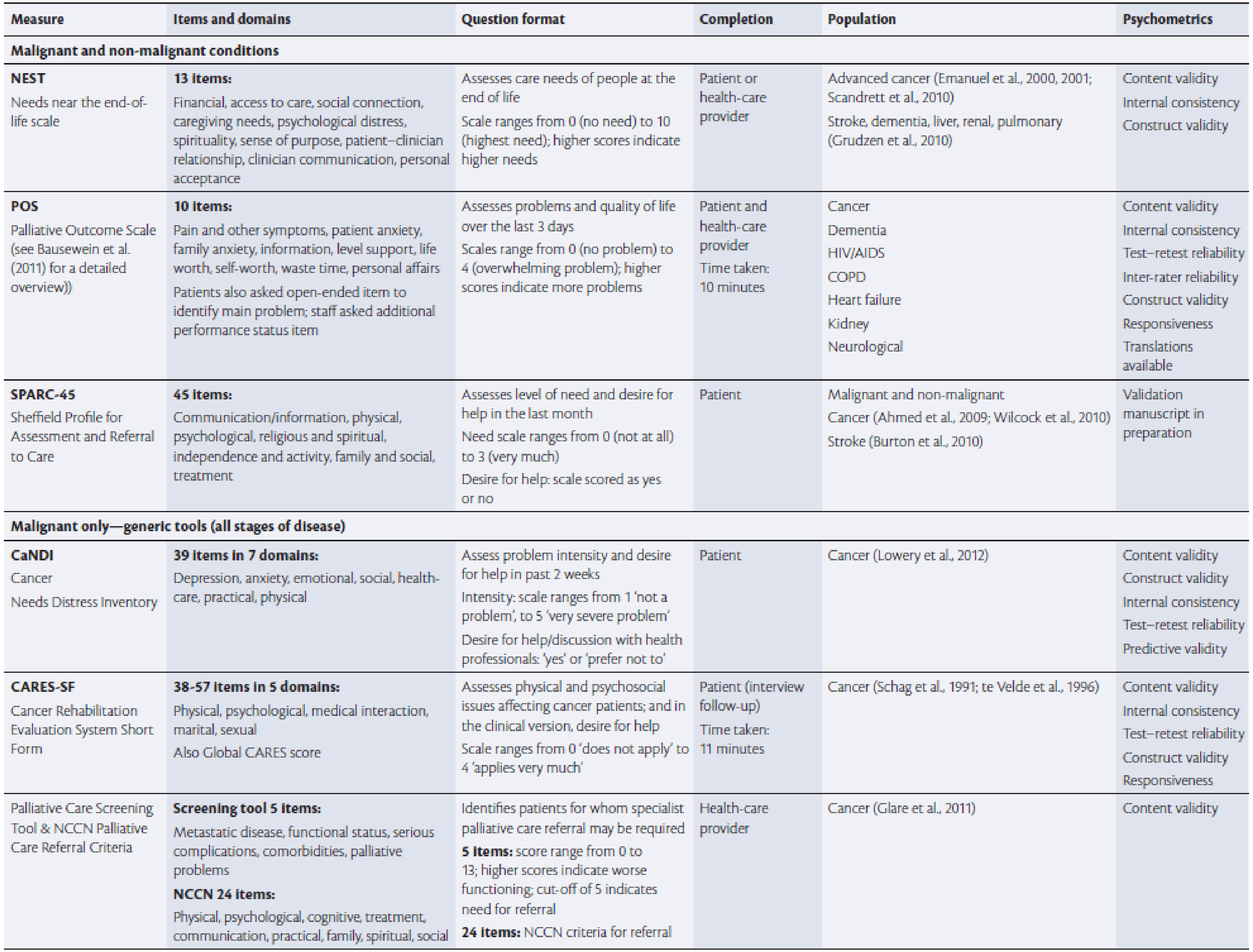
No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name ______________________________

Date ________________ Time ________________

Complete by *(check one)*
☐ Patient
☐ Caregiver
☐ Caregiver assisted

Other tools available



Measure	Items and domains	Question format	Completion	Population	Psychometrics
Malignant and non-malignant conditions					
NEST Needs near the end-of-life scale	**13 items:** Financial, access to care, social connection, caregiving needs, psychological distress, spirituality, sense of purpose, patient–clinician relationship, clinician communication, personal acceptance	Assesses care needs of people at the end of life Scale ranges from 0 (no need) to 10 (highest need); higher scores indicate higher needs	Patient or health-care provider	Advanced cancer (Emanuel et al., 2000, 2001; Scandrett et al., 2010) Stroke, dementia, liver, renal, pulmonary (Grudzen et al., 2010)	Content validity Internal consistency Construct validity
POS Palliative Outcome Scale (see Bausewein et al. (2011) for a detailed overview))	**10 items:** Pain and other symptoms, patient anxiety, family anxiety, information, level support, life worth, self-worth, waste time, personal affairs Patients also asked open-ended item to identify main problem; staff asked additional performance status item	Assesses problems and quality of life over the last 3 days Scales range from 0 (no problem) to 4 (overwhelming problem); higher scores indicate more problems	Patient and health-care provider Time taken: 10 minutes	Cancer Dementia HIV/AIDS COPD Heart failure Kidney Neurological	Content validity Internal consistency Test–retest reliability Inter-rater reliability Construct validity Responsiveness Translations available
SPARC-45 Sheffield Profile for Assessment and Referral to Care	**45 items:** Communication/information, physical, psychological, religious and spiritual, independence and activity, family and social, treatment	Assesses level of need and desire for help in the last month Need scale ranges from 0 (not at all) to 3 (very much) Desire for help: scale scored as yes or no	Patient	Malignant and non-malignant Cancer (Ahmed et al., 2009; Wilcock et al., 2010) Stroke (Burton et al., 2010)	Validation manuscript in preparation
Malignant only—generic tools (all stages of disease)					
CaNDI Cancer Needs Distress Inventory	**39 items in 7 domains:** Depression, anxiety, emotional, social, health-care, practical, physical	Assess problem intensity and desire for help in past 2 weeks Intensity: scale ranges from 1 'not a problem', to 5 'very severe problem' Desire for help/discussion with health professionals: 'yes' or 'prefer not to'	Patient	Cancer (Lowery et al., 2012)	Content validity Construct validity Internal consistency Test–retest reliability Predictive validity
CARES-SF Cancer Rehabilitation Evaluation System Short Form	**38-57 items in 5 domains:** Physical, psychological, medical interaction, marital, sexual Also Global CARES score	Assesses physical and psychosocial issues affecting cancer patients; and in the clinical version, desire for help Scale ranges from 0 'does not apply' to 4 'applies very much'	Patient (interview follow-up) Time taken: 11 minutes	Cancer (Schag et al., 1991; te Velde et al., 1996)	Content validity Internal consistency Test–retest reliability Construct validity Responsiveness
Palliative Care Screening Tool & NCCN Palliative Care Referral Criteria	**Screening tool 5 items:** Metastatic disease, functional status, serious complications, comorbidities, palliative problems **NCCN 24 items:** Physical, psychological, cognitive, treatment, communication, practical, family, spiritual, social	Identifies patients for whom specialist palliative care referral may be required **5 items:** score range from 0 to 13; higher scores indicate worse functioning; cut-off of 5 indicates need for referral **24 items:** NCCN criteria for referral	Health-care provider	Cancer (Glare et al., 2011)	Content validity

In Oxford textbook of Palliative Medicine (5th ed.)

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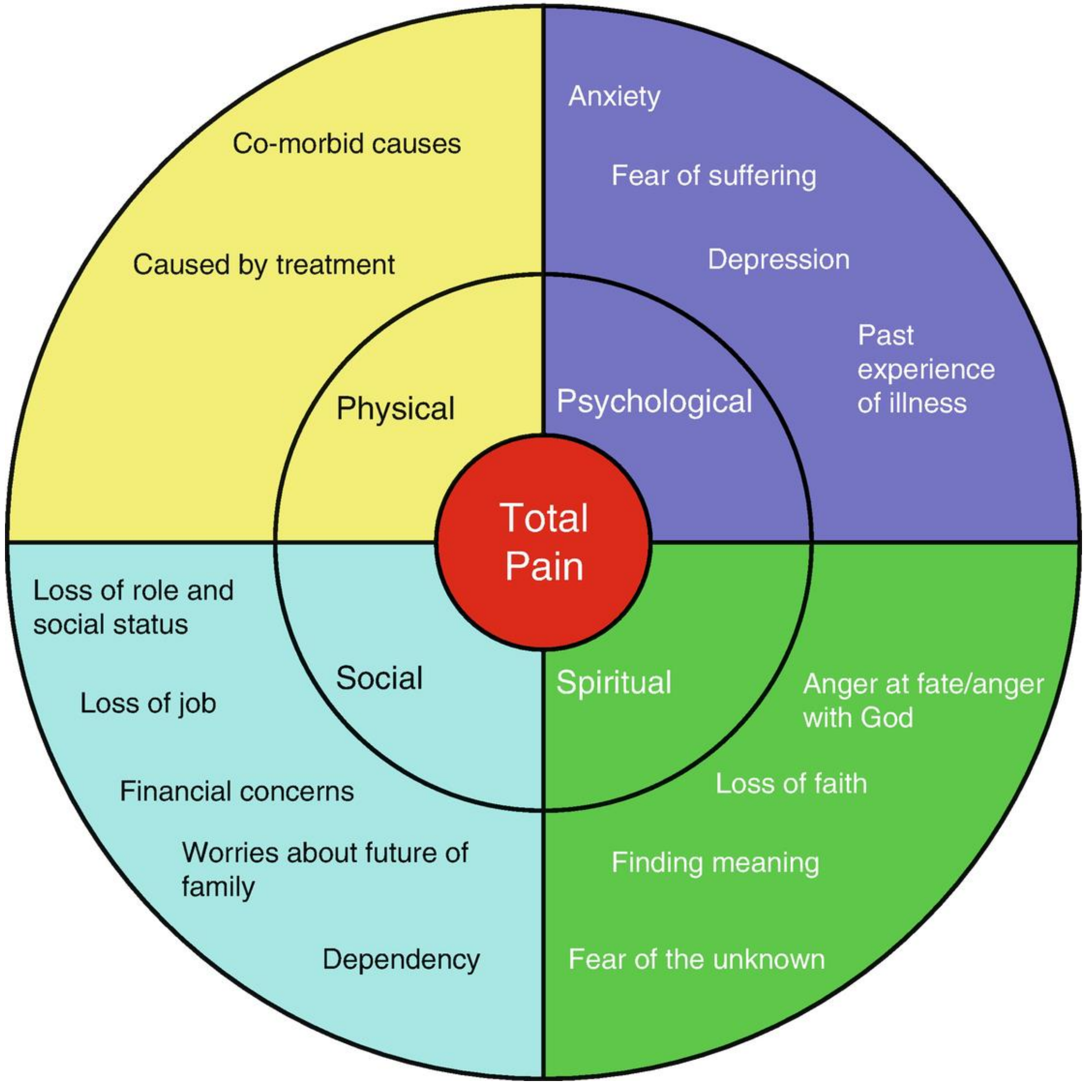
Common symptoms in EoL

- Pain
- Asthenia/ Fatigue
- Anorexia / Cachexia
- Nausea/ Vomiting
- Dyspnea
- Anxiety
- Sleep disorders
- Gastrointestinal problems
- Skin problems
- Hemptyses

PAIN



Total Pain

Physical

Co-morbid causes

Caused by treatment

Psychological

Anxiety

Fear of suffering

Depression

Past experience of illness

Social

Loss of role and social status

Loss of job

Financial concerns

Worries about future of family

Dependency

Spiritual

Anger at fate/anger with God

Loss of faith

Finding meaning

Fear of the unknown

Recognition and accurate assessment and regular reassessment

Importance of the primary caregiver as a key informant

Effective 'total pain' planning and management

A person-centred approach

- Three step process
  (1) Assessment all types of pain (physical, emotional, spiritual)…if physical, what kind?
  (2) Treat each type of pain individually, focusing on specific etiology of each
  (3) Continual reassessment of treatment goals (pain levels, goals of function, mood, sleep, social interaction, etc.)

ASSESSMENT!!!

Behind the drugs…Other non-pharmacological interventions

Massage

- A lot of people find relief from a gentle massage
- Several studies have found that massage is effective in relieving pain and other symptoms for people with serious illness

Relaxation techniques

- Guided imagery, hypnosis, biofeedback, breathing techniques, and gentle movement such as tai chi.
- Relaxation techniques are often very effective, particularly when a patient -- or a caregiver -- is feeling anxious

Acupuncture

Physical therapy

- If a person has been active before and is now confined to bed, even just moving the hands and feet a little bit can help

Pleasant experiences (ex: pet therapy)

Gel packs

- These are simple packs that can be warmed or chilled and used to ease localized pain.

ASTHENIA/ FATIGUE

Etiology of Asthenia (weakness)

Likely **multifactorial:**

- Direct tumor effects on energy
- Paraneoplastic syndromes
- Humoral and hormonal influences
- Anemia
- Chronic infections
- Sleep disturbances
- Fluid & electrolyte disturbances
- Drugs
- Over-exertion

Non-Pharmacological Management of Asthenia

- Among the most difficult symptoms to treat!

Develop A PLAN WITH PATIENT AND FAMILIES to allow them to perform enjoyed activities:

- Coordinate activities with times of most energy
- Arrange for help from family, home care, hospice, nursing home, …
- Use energy conservation strategies (occupational/physical therapy consult)
- Change medications and/or times
- Daytime rest and effective sleep at night

Anorexia/Cachexia Syndrome

Anorexia/Cachexia Syndrome

Inflammatory process, loss of fat and muscle tissue

Characteristics:

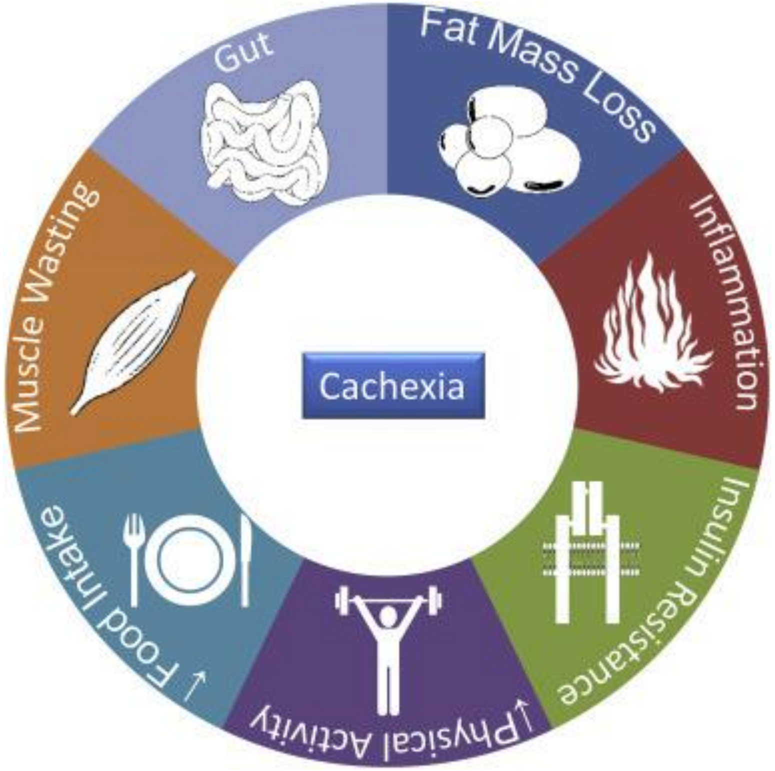
- anorexia (loss of appetite),
- Weight of loss,fatigue, chronic nausea

- Very common in advanced illness
- Frequently associated with asthenia
- May be seen as sign of “failure” or “giving up”

NOTE THAT:

- Increased nutrition often does NOT reverse or improve cachexia
- Increased nutrition will not halt disease progression

- **Etiologies not well understood**



Anorexia/Cachexia- Treatment

Search for and treat specific causes contributing to secondary cachexia:

1. Nausea/vomiting
2. Anxiety
3. Pain
4. Constipation/diarrhea

If no specific cause found, treatment if:

1. QoL= enjoyment of food
2. To give sense of normalcy in daily living

Non-Pharmacological Interventions

- Patient and caregivers **Education**:
  - 1. Common part of dying process
  - 2. Natural endorphins prevent hunger

- Encourage favorite foods
- Avoid:
  - disagreeable or nauseating smells
  - gastric irritants: e.g. spicy foods, milk, coffee
- Frequent and small meals

Pharmacological Interventions (main objective: Appetite Stimulation)

- Nutritional supplements
- And others

NAUSEA/ VOMITING

Nausea/Vomiting

Nausea: caused by stimulation of Gastrointestinal lining, chemoreceptor trigger zone in base of fourth ventricle, vestibular apparatus or cerebral córtex

Vomiting: a neuromuscular reflex centered in the medulla oblongata

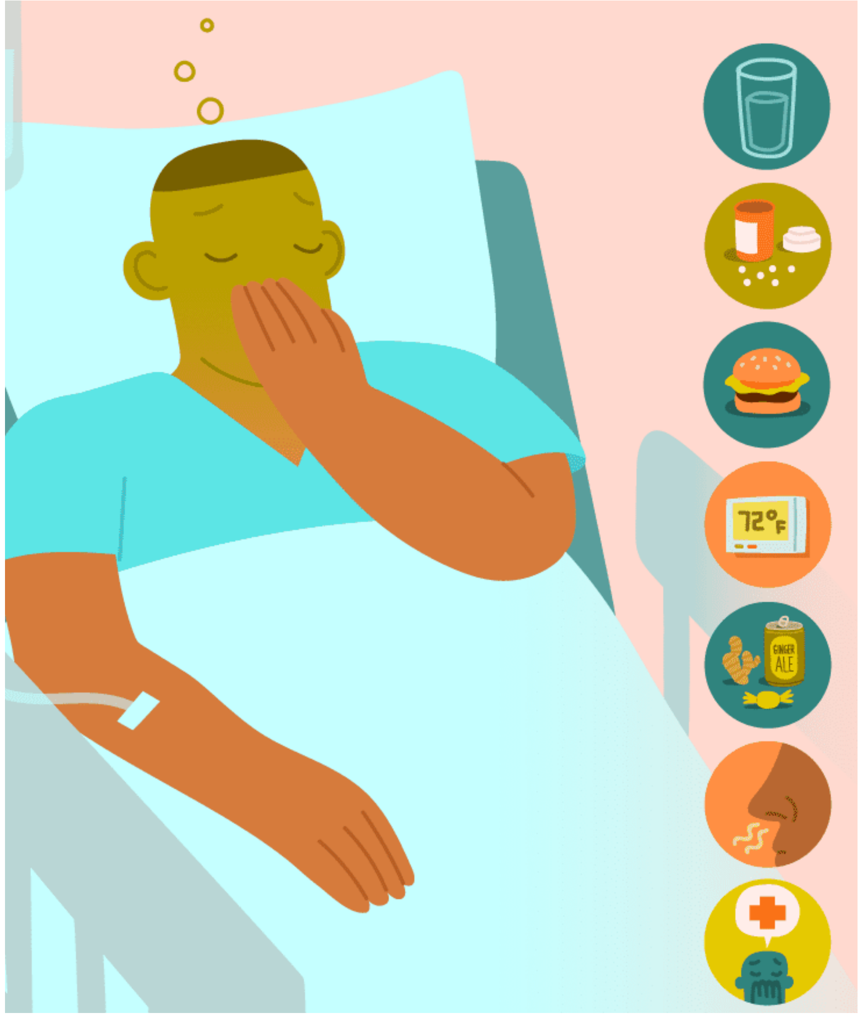
Several etiologies

(eg: mestastases, movement, medications, obstruction, metabolic,…)

Nausea/Vomiting —Non- Pharmacological Interventions:

- Decrease noxious stimuli (eg: odors, noise,…)
- Fresh air
- Limit fluids with food
- Oral care after each emesis (vomit)
- Relaxation/Cognitive Training

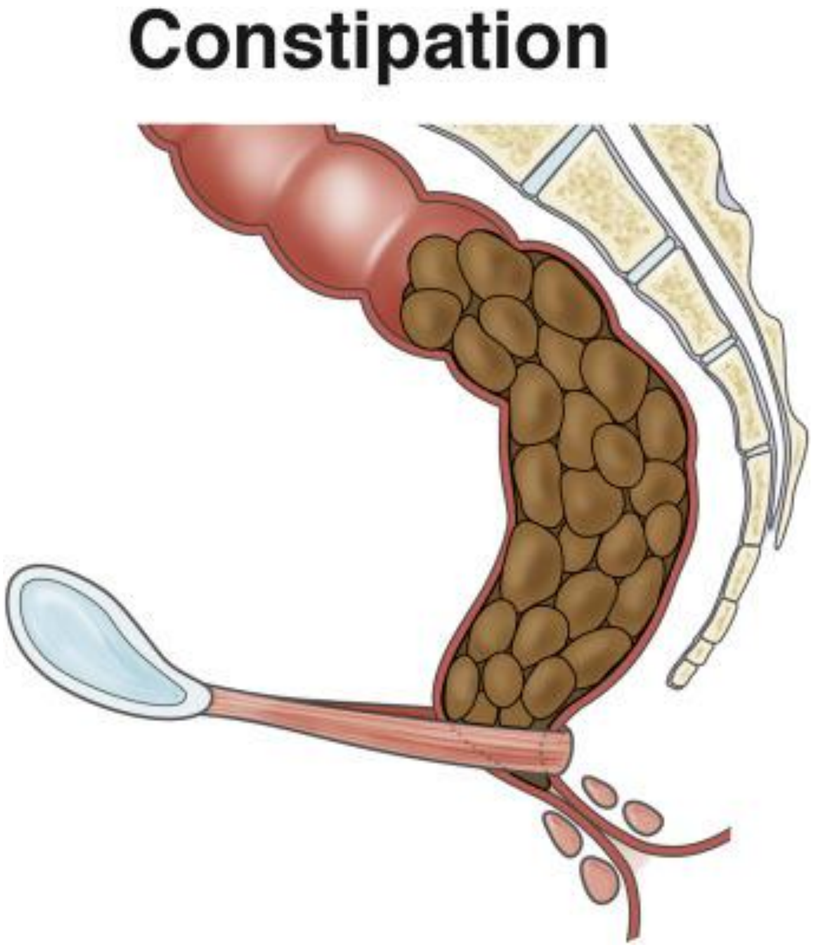
- Complementary therapies (eg: Acupuncture)
- Evidence of benefit???



GASTROINTESTINAL PROBLEMS

Constipation

Presents as:
- pain
- bloating
- nausea, vomiting
- overflow incontinence
- tenesmus
- fecal impaction
- bowel obstruction



Constipation — Treatment

Rectal exam to detect:

- stool mass
- fecal impaction
- Hypotonia

- Treatment of causes not appropriate in advanced illness
- Tailor investigations and treatment to stage of illness

Non-Pharmacological interventions:

- Scheduled toileting
- Position: sit up
- Encourage fluid intake if not in advanced stages of illness

Diarrhea

- More than 3 loose stools/ 24-hour period
- Less common than constipation
- If occurs > 3 weeks = chronic
- At EOL commonly due to overuse of laxatives or infection/bacteria or Candida overgrowth

- May lead to:
  - dehydration
  - malabsorption
  - fatigue
  - hemorrhoids
  - perianal skin breakdown
  - electrolyte imbalance

Non-Pharmacological Interventions

- Rehydration, electrolyte correction
- Avoid milk, gas forming foods
- Hold laxatives
- Consider bulk agents such as bran but use with caution

DYSPNEA

Dyspnea

- Most frightening symptom for patients, families and healthcare providers
- Experience may not correlate with any measures of severity OR perceptions of loved ones
- Importance impact to QoL: ask about exercise tolerance, activities, daily life,…

Dyspnea — Treatment

- Non-pharmacological and pharmacological

- Exacerbated by anxiety (patient and family!)
- **Educate:**
    1. Experience may not equal perception
    2. Etiologies
    3. Changes in respiratory patterns may not equal dyspnea
    4. Drugs will remove perception of dyspnea but may not alter respiratory pattern

Non-Pharmacological Interventions

- Avoid exacerbating activities BUT need to be sensitive to isolation
- Limit people in room
- Reduce room temperature and maintain humidity
- Open a window and allow to see outside
- Use a fan gently blowing across face
- Avoid irritants (eg: smoke, dry air,…)
- Elevate head of bed
- Relaxation therapy

Pharmacological Interventions

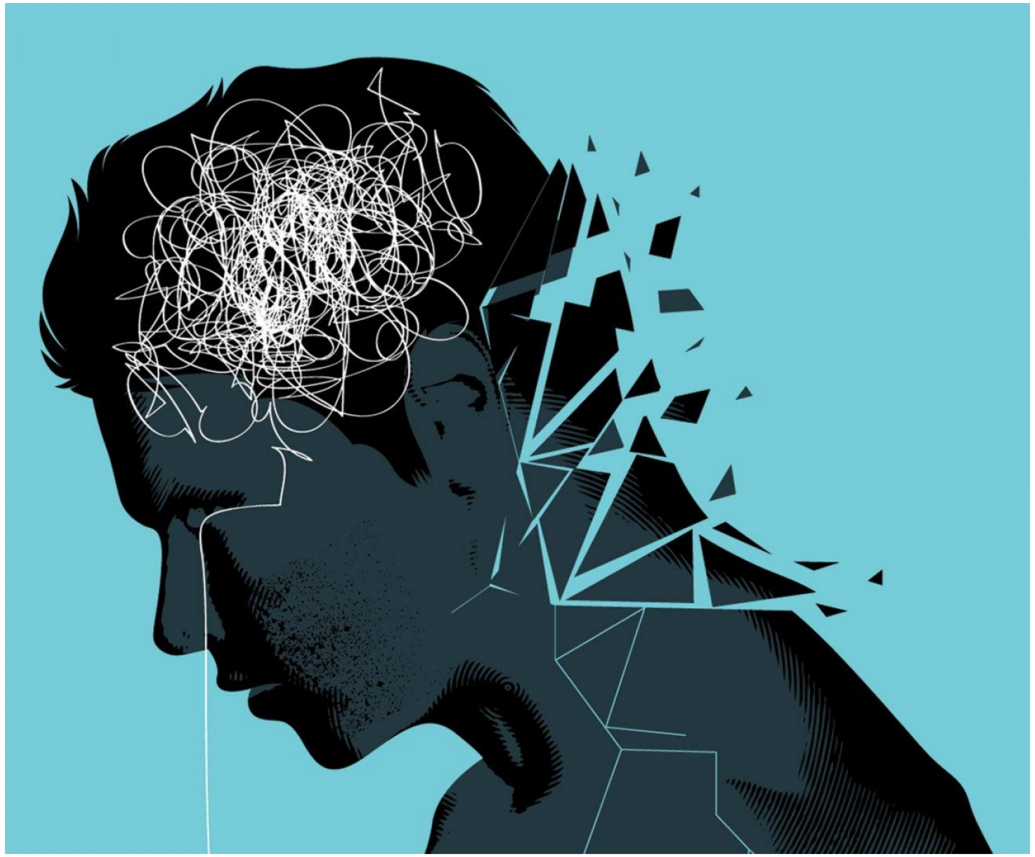
Oxygen: may help even if not necessary
Opioids: to decrease perception of dyspnea
Benzodiazepines/Anxiolytics:
decrease anxiety
decrease thoraco-abdominal response

ANXIETY

Signs and Symptoms

- Apprehension, excessive worry
- Irritability, tension
- Insomnia
- Tachycardia
- Hyperventilation, shortness of breath
- Gastrointestinal distress, nausea

- Important impact in symptom management and QoL



Non pharmacological interventions

Communication is the Key:

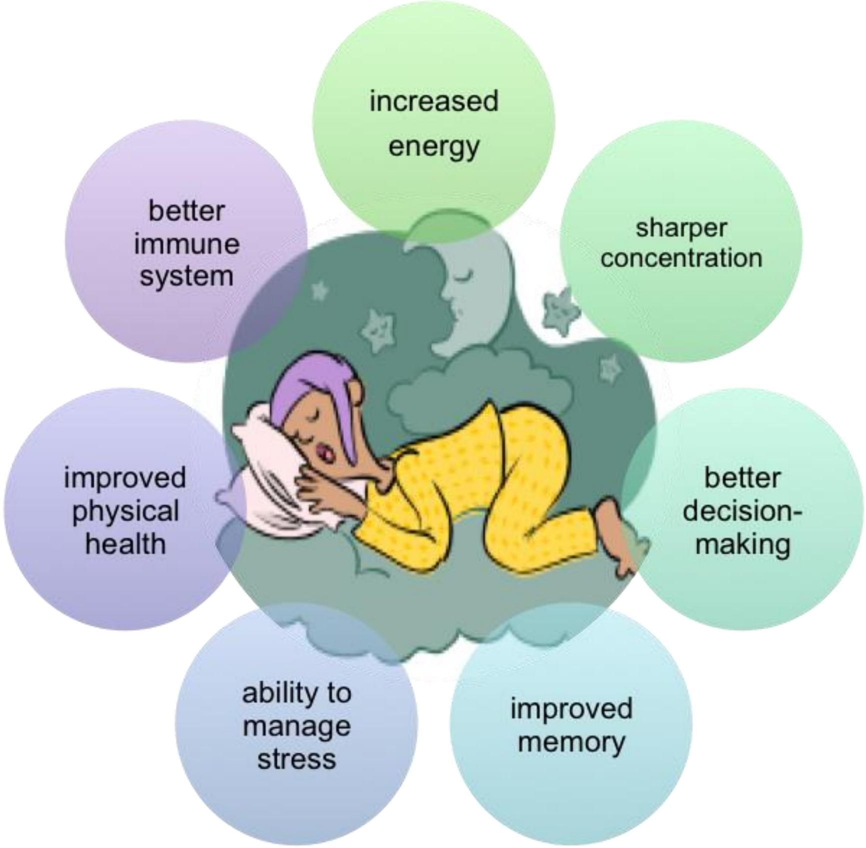
- Listening
- Finding out what they (patient and family Know/ need to know)
- Finding out their concerns
- Being honest
- Reassuring where possible
- Spiritual distress
- Patients who undertand about their condition are less anxious

SLEEP DISORDERS

Sleep Disturbances

Frequently caused by:

- Anxiety
- Pain
- Uncontrolled symptoms
- Fears of future (fear of death)
- Grief



NOTE THAT:

- Emotional and psychological/ spiritual assessment and support are fundamental
- May exacerbate asthenia and achievement of other symptom management
- Sleep history is important

Non-Pharmacological Interventions

- Regular schedule
- Naps allowed BUT avoid sleeping all day
- Control symptoms
- Avoid:
  - mental stimulation AND distress at night
  - Stimulants (eg: alcohol, steroids, coffee, metamphetamines, specially at night)
- Increase daytime physical activity (if possible: occupational therapy, phisyotherapy,…)
- Relaxation therapy, music, imagery
- Extra bedding in case of cold

SKIN PROBLEMS

Skin Ulcers

- Skin care is poorly taught, and frequently is relegated to the nursing team
- Cause of:
  - significant pain
  - exsudate
  - Bleeding
  - Odors (which improve isolation)
  - Infections
  - Psychological trauma
- MANAGEMENT IS PREVENTIVE!
- TEAM APPROACH

Skin — Practical aspects in treatment/ management

- Keep skin clean and dry
- Protect pressure points
- Use draw sheets to move/turn patient
- Special mattresses – air or air flotation
- Improve the best comestic effect possible to boost confidence
- Attention to lifestyle and psychological effects

HEMOPTYSES

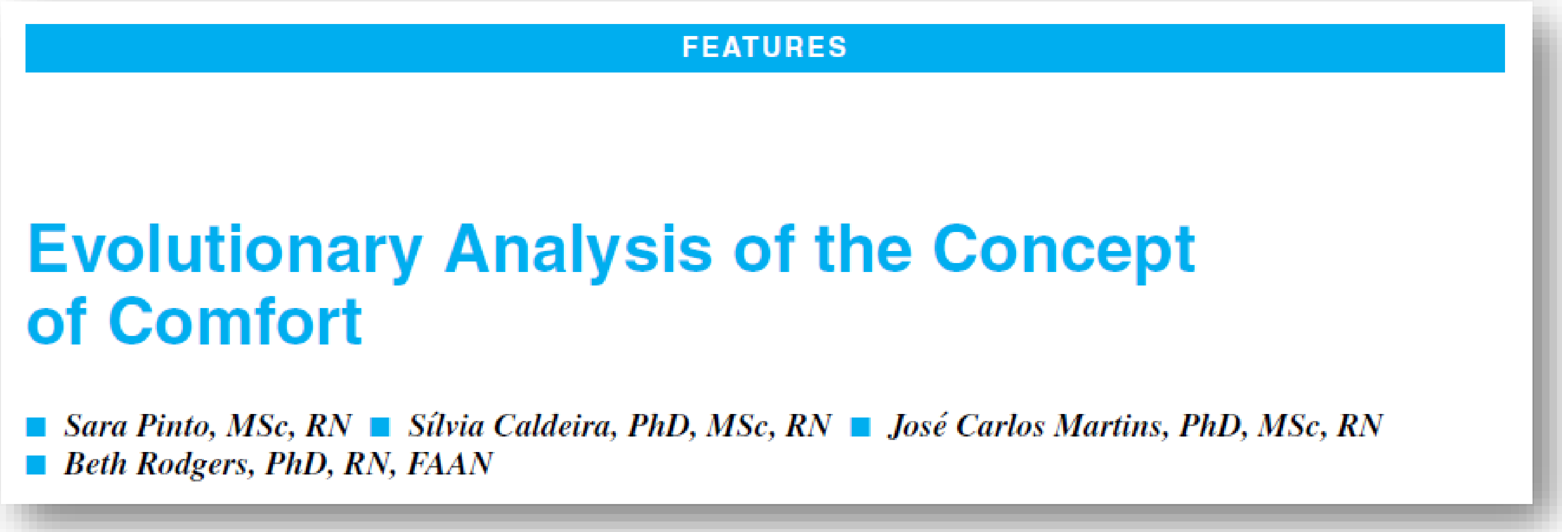
Hemoptysis

- Ranges from streaking of sputum to massive bleeding > 200 cc/24 hours
- Frightening!

- If massive :
  - Medical Doctor/ nurse/ caregiver at bedside
  - Opioids/ Benzodiazepines iv/sc push
- Hide with dark towels

Comfort measures in the final stage of life

Care in agonizing phase



FEATURES

Evolutionary Analysis of the Concept of Comfort

■ *Sara Pinto, MSc, RN* ■ *Sílvia Caldeira, PhD, MSc, RN* ■ *José Carlos Martins, PhD, MSc, RN*
■ *Beth Rodgers, PhD, RN, FAAN*

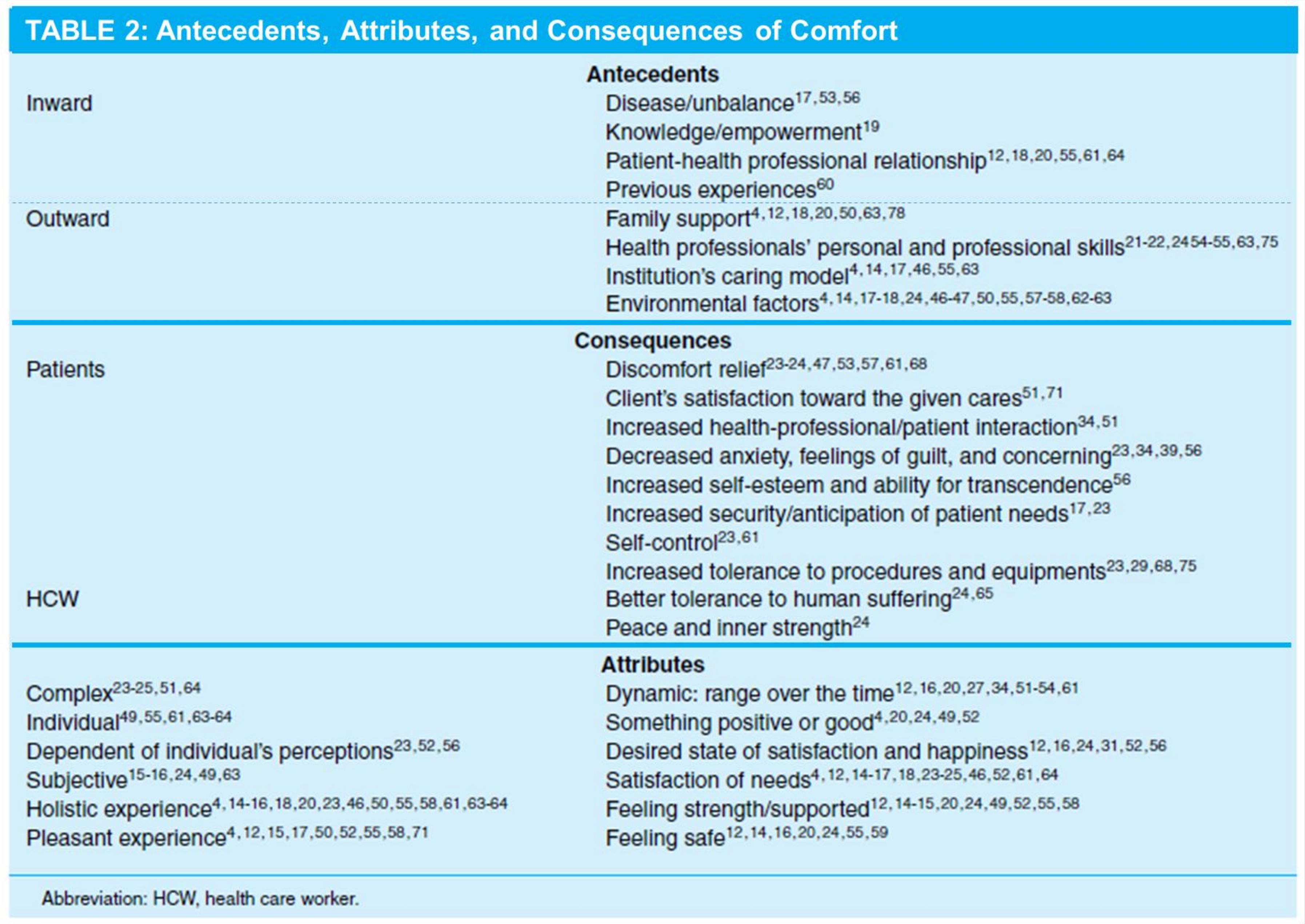


TABLE 2: Antecedents, Attributes, and Consequences of Comfort

	Antecedents
Inward	Disease/unbalance[17,53,56]
	Knowledge/empowerment[19]
	Patient-health professional relationship[12,18,20,55,61,64]
	Previous experiences[60]
Outward	Family support[4,12,18,20,50,63,78]
	Health professionals' personal and professional skills[21-22,2454-55,63,75]
	Institution's caring model[4,14,17,46,55,63]
	Environmental factors[4,14,17-18,24,46-47,50,55,57-58,62-63]
	Consequences
Patients	Discomfort relief[23-24,47,53,57,61,68]
	Client's satisfaction toward the given cares[51,71]
	Increased health-professional/patient interaction[34,51]
	Decreased anxiety, feelings of guilt, and concerning[23,34,39,56]
	Increased self-esteem and ability for transcendence[56]
	Increased security/anticipation of patient needs[17,23]
	Self-control[23,61]
	Increased tolerance to procedures and equipments[23,29,68,75]
HCW	Better tolerance to human suffering[24,65]
	Peace and inner strength[24]
	Attributes
Complex[23-25,51,64]	Dynamic: range over the time[12,16,20,27,34,51-54,61]
Individual[49,55,61,63-64]	Something positive or good[4,20,24,49,52]
Dependent of individual's perceptions[23,52,56]	Desired state of satisfaction and happiness[12,16,24,31,52,56]
Subjective[15-16,24,49,63]	Satisfaction of needs[4,12,14-17,18,23-25,46,52,61,64]
Holistic experience[4,14-16,18,20,23,46,50,55,58,61,63-64]	Feeling strength/supported[12,14-15,20,24,49,52,55,58]
Pleasant experience[4,12,15,17,50,52,55,58,71]	Feeling safe[12,14,16,20,24,55,59]

Abbreviation: HCW, health care worker.

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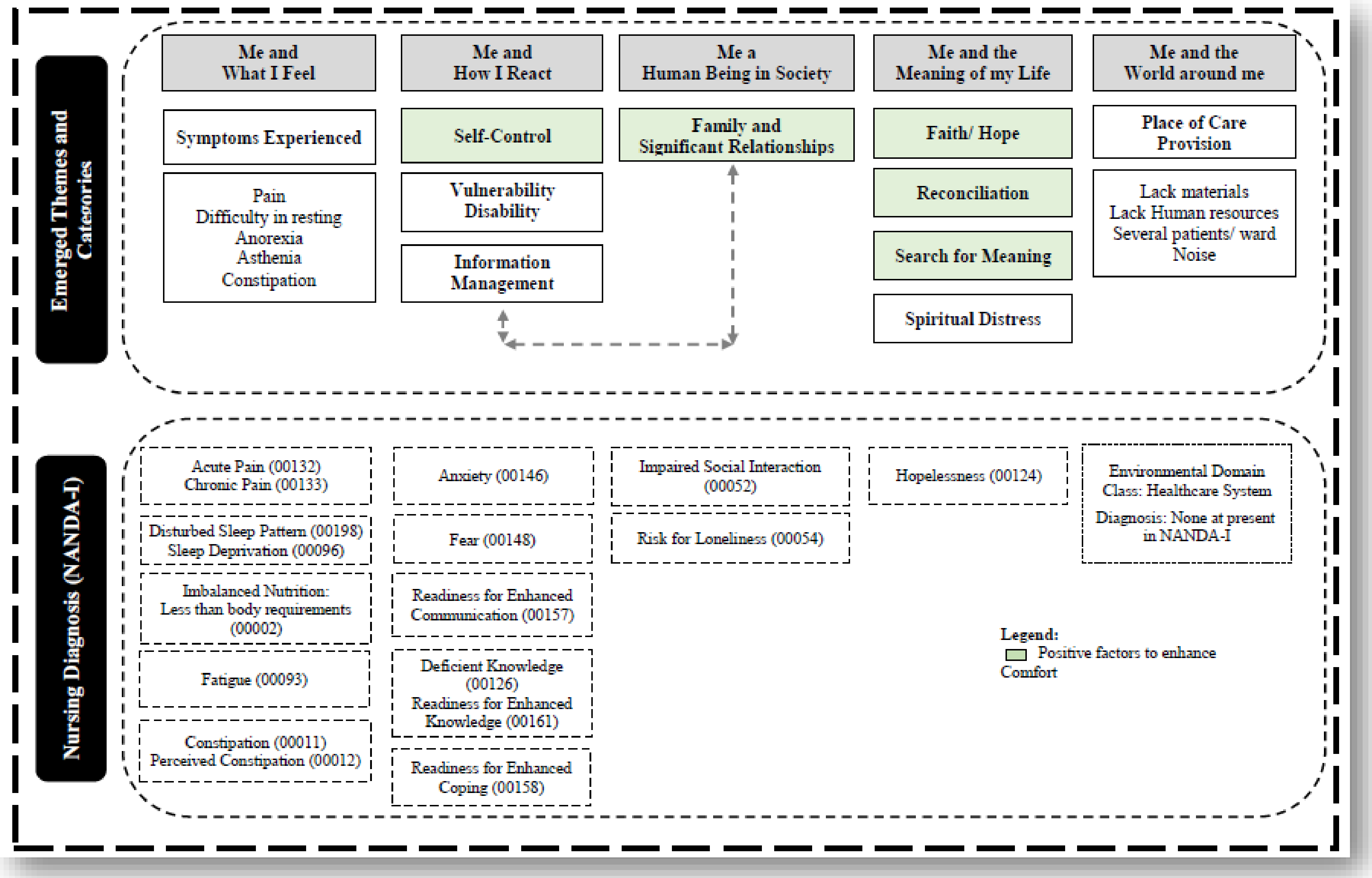
ORIGINAL RESEARCH

A qualitative study about palliative care patients' experiences of comfort: Implications for nursing diagnosis and interventions

Sara Pinto *[1,2], Sílvia Caldeira[3], José Carlos Martins[4,5]



	Me and What I Feel	Me and How I React	Me a Human Being in Society	Me and the Meaning of my Life	Me and the World around me
Emerged Themes and Categories	Symptoms Experienced	Self-Control	Family and Significant Relationships	Faith/ Hope	Place of Care Provision
	Pain Difficulty in resting Anorexia Asthenia Constipation	Vulnerability Disability		Reconciliation	Lack materials Lack Human resources Several patients/ ward Noise
		Information Management		Search for Meaning	
				Spiritual Distress	
Nursing Diagnosis (NANDA-I)	Acute Pain (00132) Chronic Pain (00133)	Anxiety (00146)	Impaired Social Interaction (00052)	Hopelessness (00124)	Environmental Domain Class: Healthcare System Diagnosis: None at present in NANDA-I
	Disturbed Sleep Pattern (00198) Sleep Deprivation (00096)	Fear (00148)	Risk for Loneliness (00054)		
	Imbalanced Nutrition: Less than body requirements (00002)	Readiness for Enhanced Communication (00157)			
	Fatigue (00093)	Deficient Knowledge (00126) Readiness for Enhanced Knowledge (00161)			
	Constipation (00011) Perceived Constipation (00012)	Readiness for Enhanced Coping (00158)			

Legend:
🟩 Positive factors to enhance Comfort

Original Article

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Comfort Measures Only: Agreeing on a Common Definition Through a Survey

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Abstract

Despite how frequently we say "comfort measures only" (CMO) in the hospital setting, review of the medical literature yields poor representation and definition of the term. Through a survey in our hospital center, we aimed at understanding what doctors understand as CMO. A total of 176 physicians responded to the survey. We asked them about the moment in the patient care timeline when to use it and what degree of respiratory support, laboratory draws, antibiotic therapy, level of care, and code status should be a part of it. Disparities in responses were the norm, and common defining characteristics were the exception.

Keywords

comfort, palliative, hospice, goals, death, noninvasive


10

“ Comfort measures only is the level of care offered to a patient when life expectancy is weeks to months or less, consisting of:

oxygen per nasal cannula, oral nutrition and hydration as tolerated, no blood draws regardless of indication, no transfer to critical care unit, optional case-based antibiotics therapy, opioids for maximal symptom relief and ideally DNR/DNI.”

Recognizing the terminal phase (last days of life)

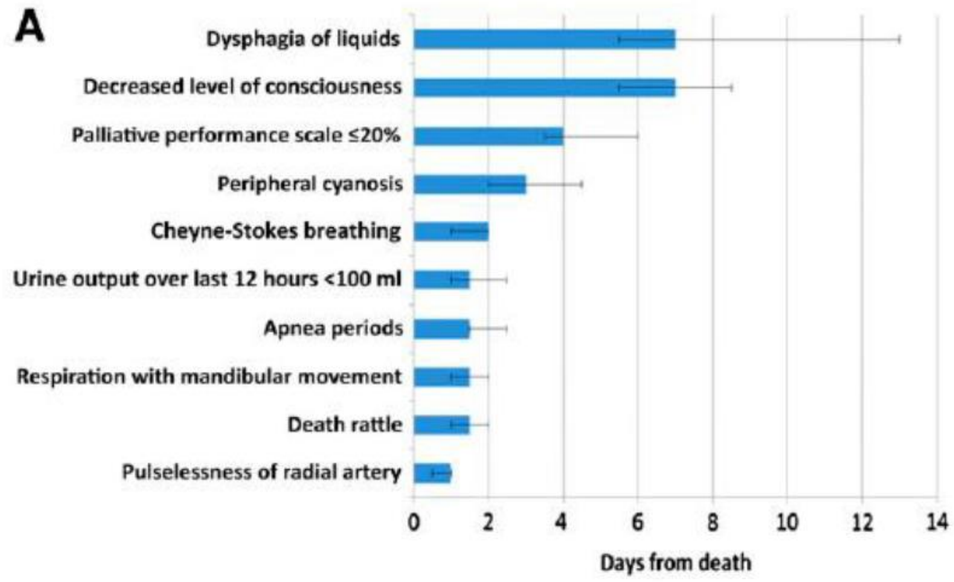
?

THE END OF LIFE				THE DYING PHASE
At risk of dying in 6 – 12 months, but may live for years	**MONTHS** 2 – 9 months	**SHORT WEEKS** 1 – 8 weeks	**LAST DAYS** 2 – 14 days	**LAST HOURS** 0 – 48 hours
DISEASE(S) RELENTLESS Progression is less reversible Treatment benefits are waning	**CHANGE UNDERWAY** Benefit of treatment less evident Harms of treatment less tolerable	**RECOVERY LESS LIKELY** The risk of death is rising	**DYING BEGINS** Deterioration is weekly/daily	**ACTIVELY DYING** The body is shutting down The person is letting go

- The terminal phase is defined as a period of irreversible decline in functional status prior to death.
- The terminal phase can last from a few hours to days and very occasionally to weeks.

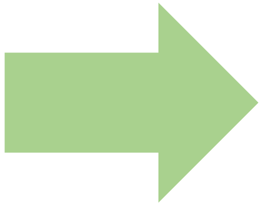
- Worsening of certain symptoms is indicative of entering the terminal phase:
    - weight loss
    - profound weakness and fatigue
    - social withdrawal
    - disinterest in food and drink
    - dysphagia and difficulty in swallowing medication
    - refractory delirium
    - changes in breathing
    - drowsy for extended periods
    - reduced urine output
    - skin that is cool to touch
    - a waxy look to the skin

Clinical Signs of Impending Death in Cancer Patients



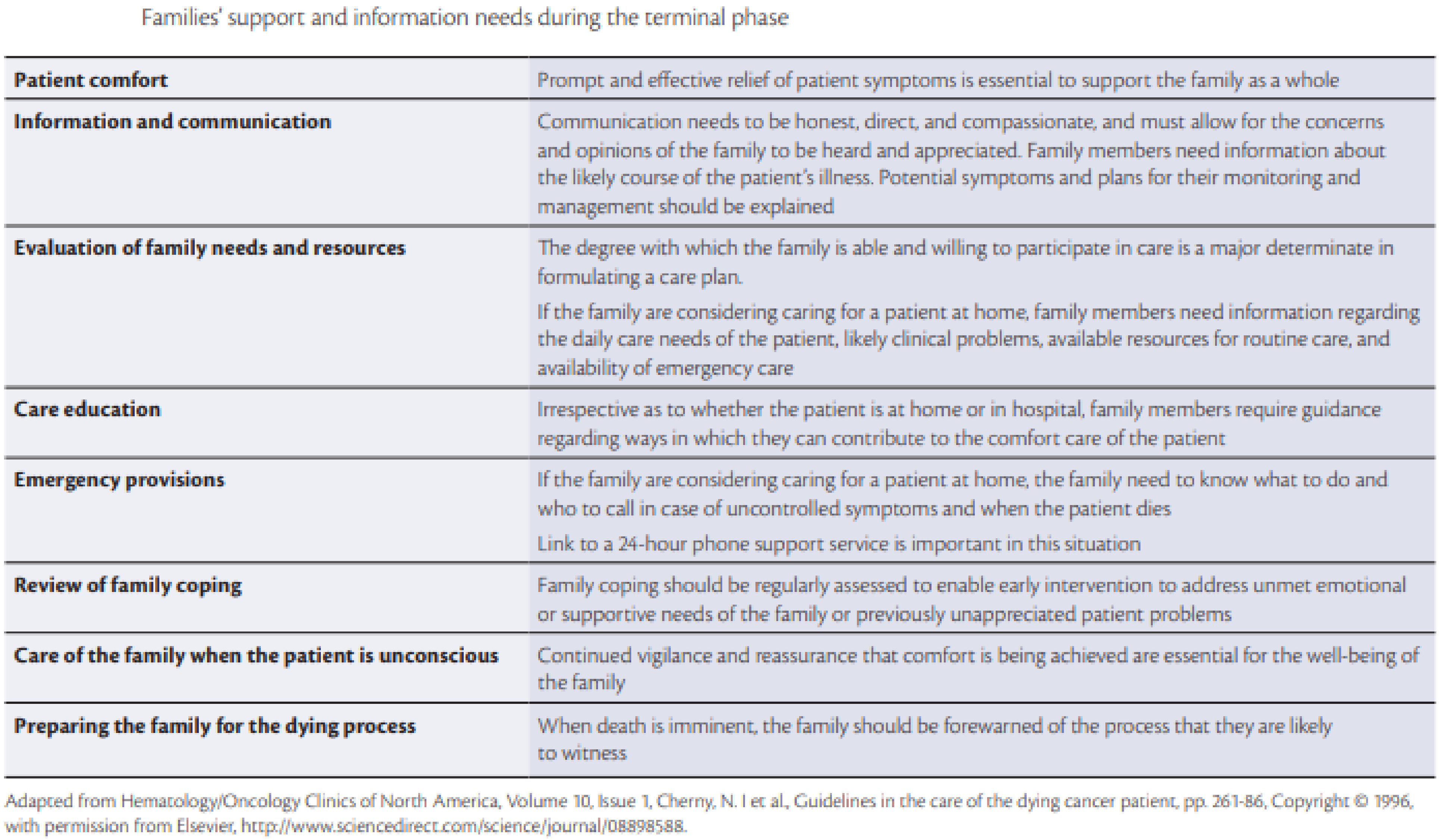
Frequent Problems:

- Insensitive communication about prognosis
- Poorly symptom management
- Inadequate therapies
- Uncomfortable environment



- Optimization of communication skills
- Involvement of the patient/caregivers
- Encouraging family participation
- Improvement of technical skills

- Preparing the family and family well-being
- Discussing advanced care planning and resuscitation
- Anticipated dying
- Advanced care planning for patients with unanticipated threatening events
- Identifying substitute decision-makers and advance care planning
- Symptoms management in the final days of life



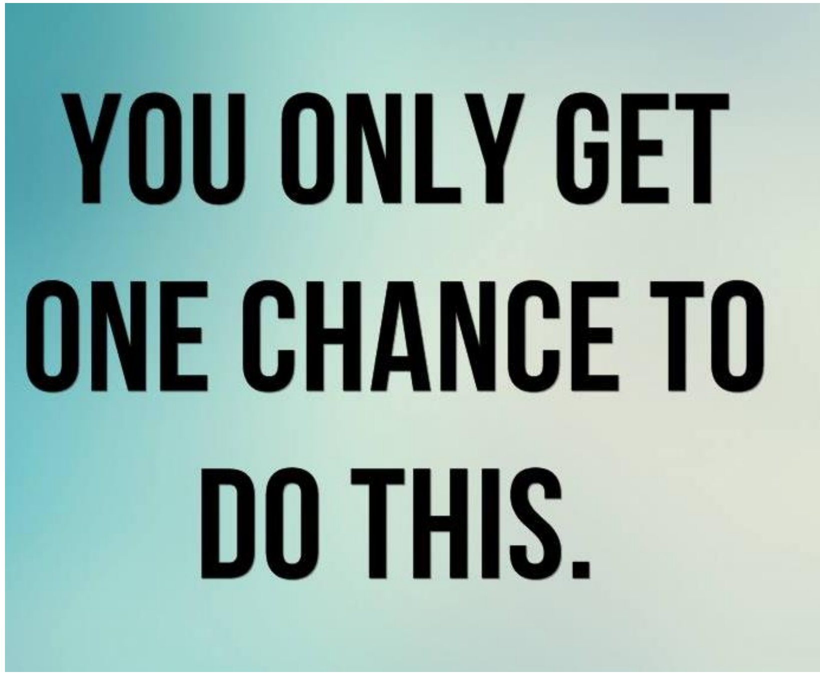
Families' support and information needs during the terminal phase

Patient comfort	Prompt and effective relief of patient symptoms is essential to support the family as a whole
Information and communication	Communication needs to be honest, direct, and compassionate, and must allow for the concerns and opinions of the family to be heard and appreciated. Family members need information about the likely course of the patient's illness. Potential symptoms and plans for their monitoring and management should be explained
Evaluation of family needs and resources	The degree with which the family is able and willing to participate in care is a major determinate in formulating a care plan. If the family are considering caring for a patient at home, family members need information regarding the daily care needs of the patient, likely clinical problems, available resources for routine care, and availability of emergency care
Care education	Irrespective as to whether the patient is at home or in hospital, family members require guidance regarding ways in which they can contribute to the comfort care of the patient
Emergency provisions	If the family are considering caring for a patient at home, the family need to know what to do and who to call in case of uncontrolled symptoms and when the patient dies Link to a 24-hour phone support service is important in this situation
Review of family coping	Family coping should be regularly assessed to enable early intervention to address unmet emotional or supportive needs of the family or previously unappreciated patient problems
Care of the family when the patient is unconscious	Continued vigilance and reassurance that comfort is being achieved are essential for the well-being of the family
Preparing the family for the dying process	When death is imminent, the family should be forewarned of the process that they are likely to witness

Adapted from Hematology/Oncology Clinics of North America, Volume 10, Issue 1, Cherny, N. I et al., Guidelines in the care of the dying cancer patient, pp. 261-86, Copyright © 1996, with permission from Elsevier, http://www.sciencedirect.com/science/journal/08898588.

Summarizing:

- Allow The Patient To Be In The Place Of Their Choice
- Ensure The Patient Remains At The Center Of The Care
- Enable Health Professionals To Identify The Last Days/ Hours Of Life
- Assess Multidimensional Needs
- Relief Symptoms And Fears
- Family Support
- Grief Support



YOU ONLY GET ONE CHANCE TO DO THIS.

Work in inter and trans disciplinary team in palliative care

Education of user, caregivers and families/important others

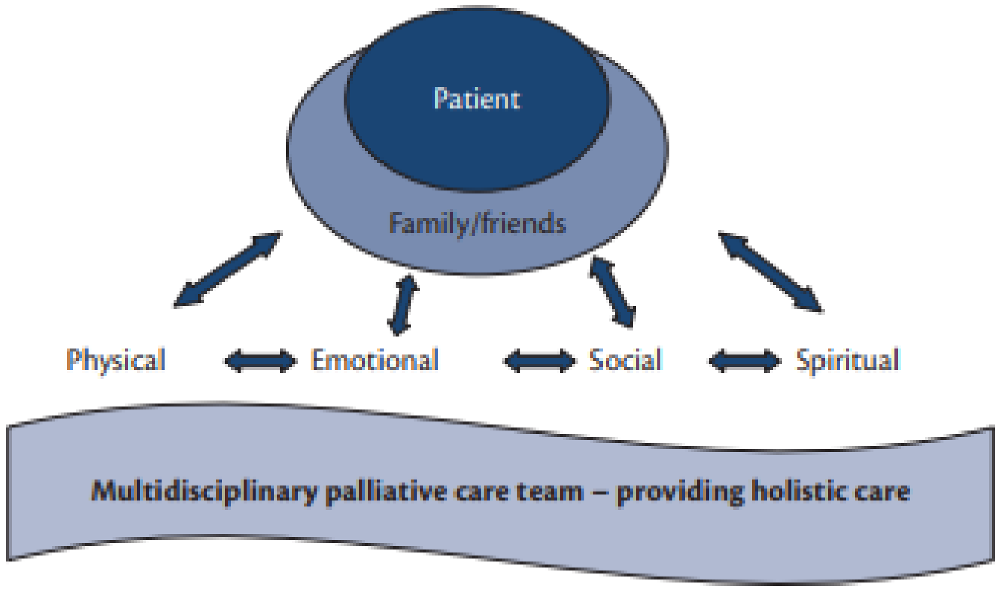


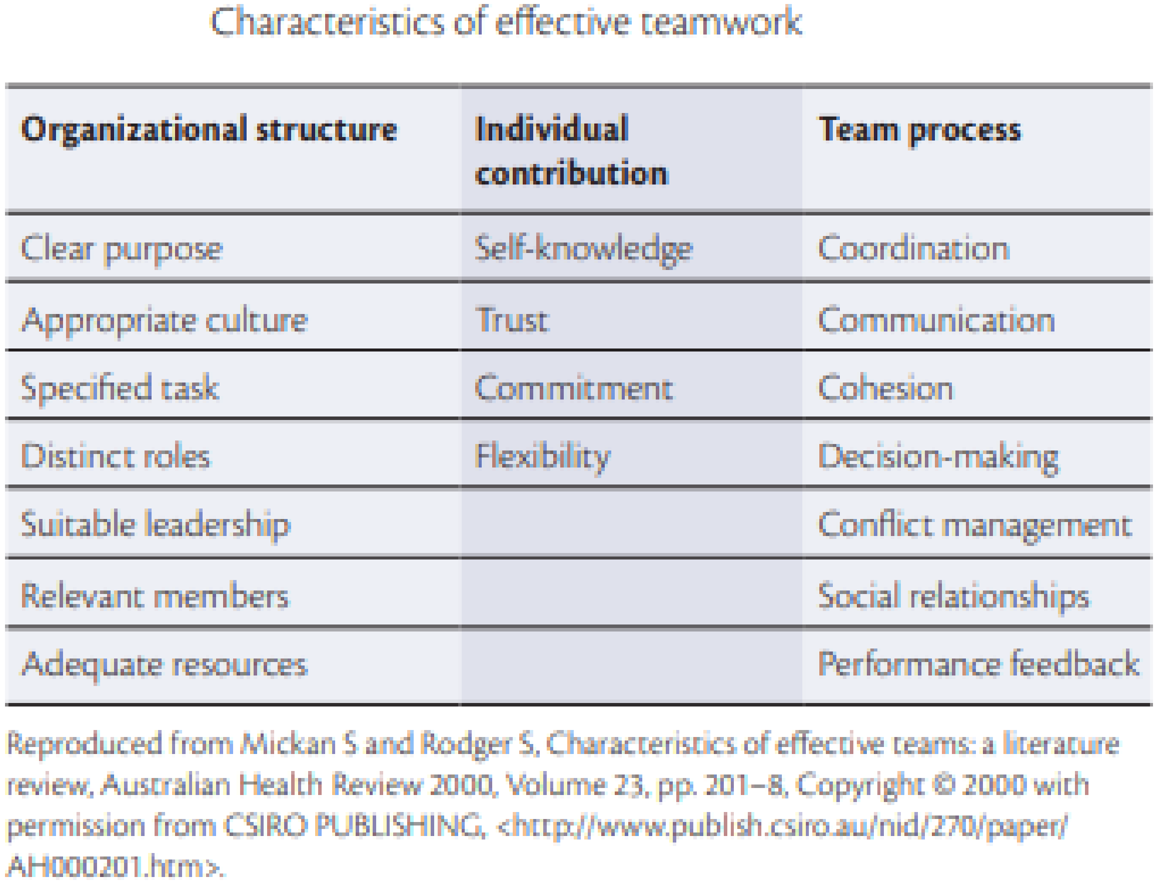
Fig. 3.2.3 Multidisciplinary palliative care team to respond to holistic patient and family needs.

The interdisciplinary team

Described as ‘an identified collective in which members **share common team goals** and **work interdependently** in planning, problem solving, decision-making, and implementing and evaluating team-related tasks’

The interdisciplinary team should try to achieve the following **objectives**:

- Accurate/ speedy assessment
- Effective and integrated treatment/ care
- Efficient communication with the patient/family, with other professionals/institutions, and within the team itself
- Audit of the team’s activities and outcomes



Characteristics of effective teamwork

Organizational structure	**Individual contribution**	**Team process**
Clear purpose	Self-knowledge	Coordination
Appropriate culture	Trust	Communication
Specified task	Commitment	Cohesion
Distinct roles	Flexibility	Decision-making
Suitable leadership		Conflict management
Relevant members		Social relationships
Adequate resources		Performance feedback

Reproduced from Mickan S and Rodger S, Characteristics of effective teams: a literature review, Australian Health Review 2000, Volume 23, pp. 201–8, Copyright © 2000 with permission from CSIRO PUBLISHING, <http://www.publish.csiro.au/nid/270/paper/AH000201.htm>.

The following aims are common for most CONSULT TEAMS

- To work alongside the hospital ward team by advising on symptom control and psychosocial/spiritual issues
- To support:
  - relatives in difficult situations
  - staff in difficult decisions and grief
- To educate staff/ family in PC
- To liaise with hospice /other PC services and home care services.

HOSPITAL TEAMS usually have several levels of intervention, from a consulting role to shared care and eventually transfer of care:

◆ Advice and guidance to professionals on the ward team without direct contact with patient.

◆ Single visit for assessment and advice on further plans for care, preferably with referrer. Further contacts specifically at referrer’s request.

◆ Short-term interventions with patients or families for specific problems.

◆ Ongoing contact due to multiple, complex problems requiring regular specialist assessment and interventions. In this case the team might temporarily take over patient responsibility

Patient and Family Education

Education on likely course of illness, symptoms and possible complications :

1. Decreases natural fear and anxiety of the “unknown”
2. Develops a plan to relief/control symptoms
3. Facilitates decision-making and helps plan for future
4. Helps patients and families to know when to seek prompt medical attention
5. Dispels myth that dying = unavoidable suffering

Frequent questions:

- Where do I receive palliative care?
- Does my insurance pay for palliative care?
- How do I know if palliative care is right for me?
- What can I expect from palliative care?
- Who provides palliative care?
- How does palliative care work with my own doctor?
- How do I get palliative care?

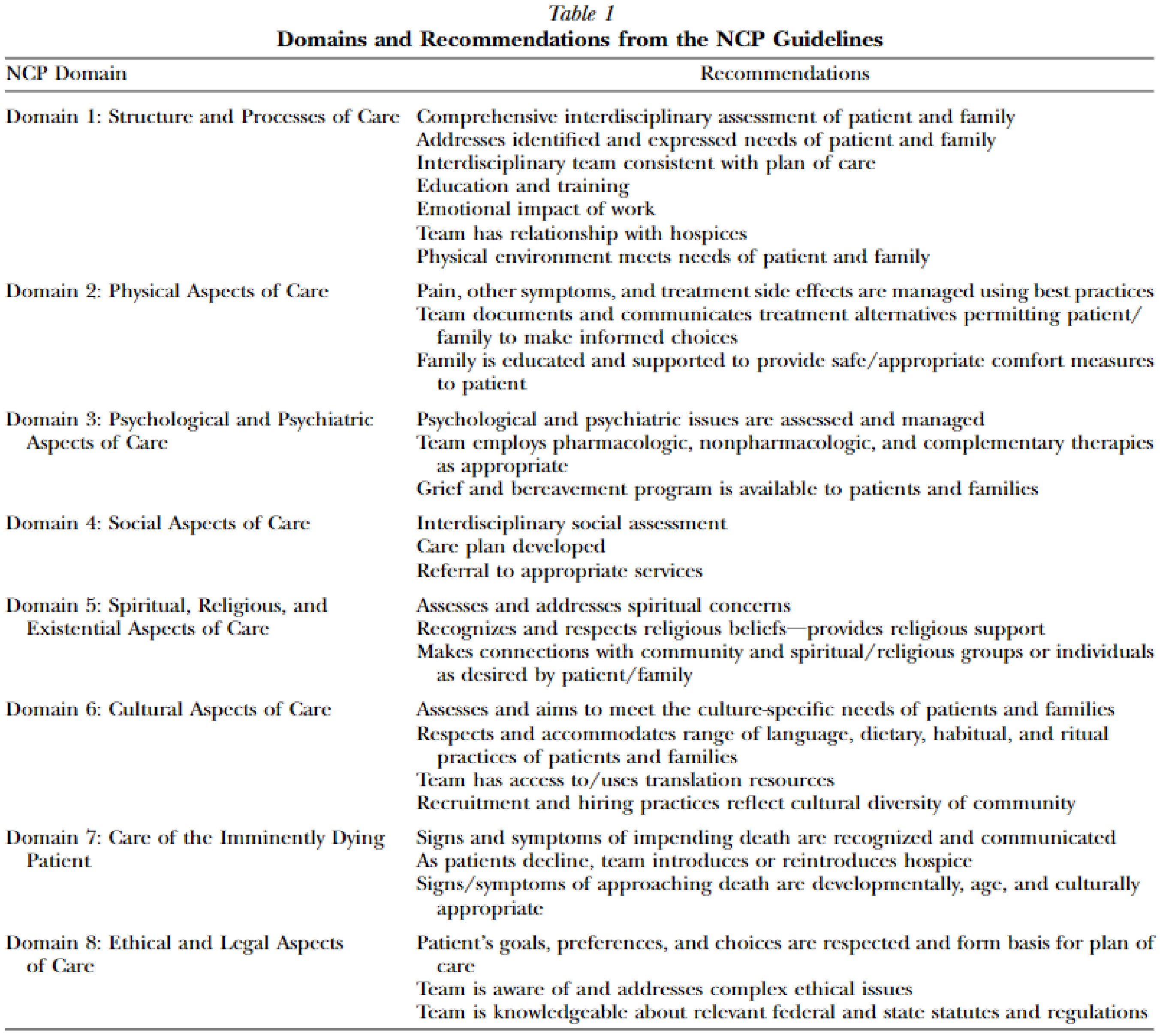


Table 1

Domains and Recommendations from the NCP Guidelines

NCP Domain	Recommendations
Domain 1: Structure and Processes of Care	Comprehensive interdisciplinary assessment of patient and family Addresses identified and expressed needs of patient and family Interdisciplinary team consistent with plan of care Education and training Emotional impact of work Team has relationship with hospices Physical environment meets needs of patient and family
Domain 2: Physical Aspects of Care	Pain, other symptoms, and treatment side effects are managed using best practices Team documents and communicates treatment alternatives permitting patient/family to make informed choices Family is educated and supported to provide safe/appropriate comfort measures to patient
Domain 3: Psychological and Psychiatric Aspects of Care	Psychological and psychiatric issues are assessed and managed Team employs pharmacologic, nonpharmacologic, and complementary therapies as appropriate Grief and bereavement program is available to patients and families
Domain 4: Social Aspects of Care	Interdisciplinary social assessment Care plan developed Referral to appropriate services
Domain 5: Spiritual, Religious, and Existential Aspects of Care	Assesses and addresses spiritual concerns Recognizes and respects religious beliefs—provides religious support Makes connections with community and spiritual/religious groups or individuals as desired by patient/family
Domain 6: Cultural Aspects of Care	Assesses and aims to meet the culture-specific needs of patients and families Respects and accommodates range of language, dietary, habitual, and ritual practices of patients and families Team has access to/uses translation resources Recruitment and hiring practices reflect cultural diversity of community
Domain 7: Care of the Imminently Dying Patient	Signs and symptoms of impending death are recognized and communicated As patients decline, team introduces or reintroduces hospice Signs/symptoms of approaching death are developmentally, age, and culturally appropriate
Domain 8: Ethical and Legal Aspects of Care	Patient's goals, preferences, and choices are respected and form basis for plan of care Team is aware of and addresses complex ethical issues Team is knowledgeable about relevant federal and state statutes and regulations

In The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum

Selfcare of professionals

- Work in PC and, in particular, EoL care is associated with inherent stressors that may impact on the well-being of healthcare providers and caregivers.

- Work stressors may have several impacts on the emotional/ spiritual and professional lives of the staff

- Stressors can adversely affect the effectiveness and quality of care and may compromise PC

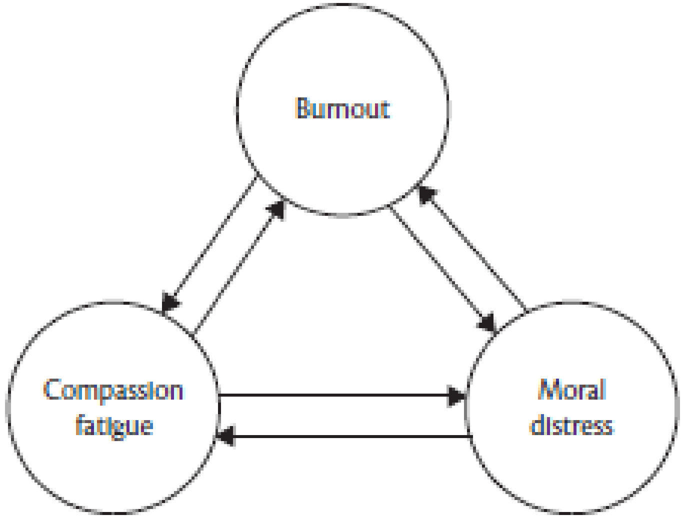
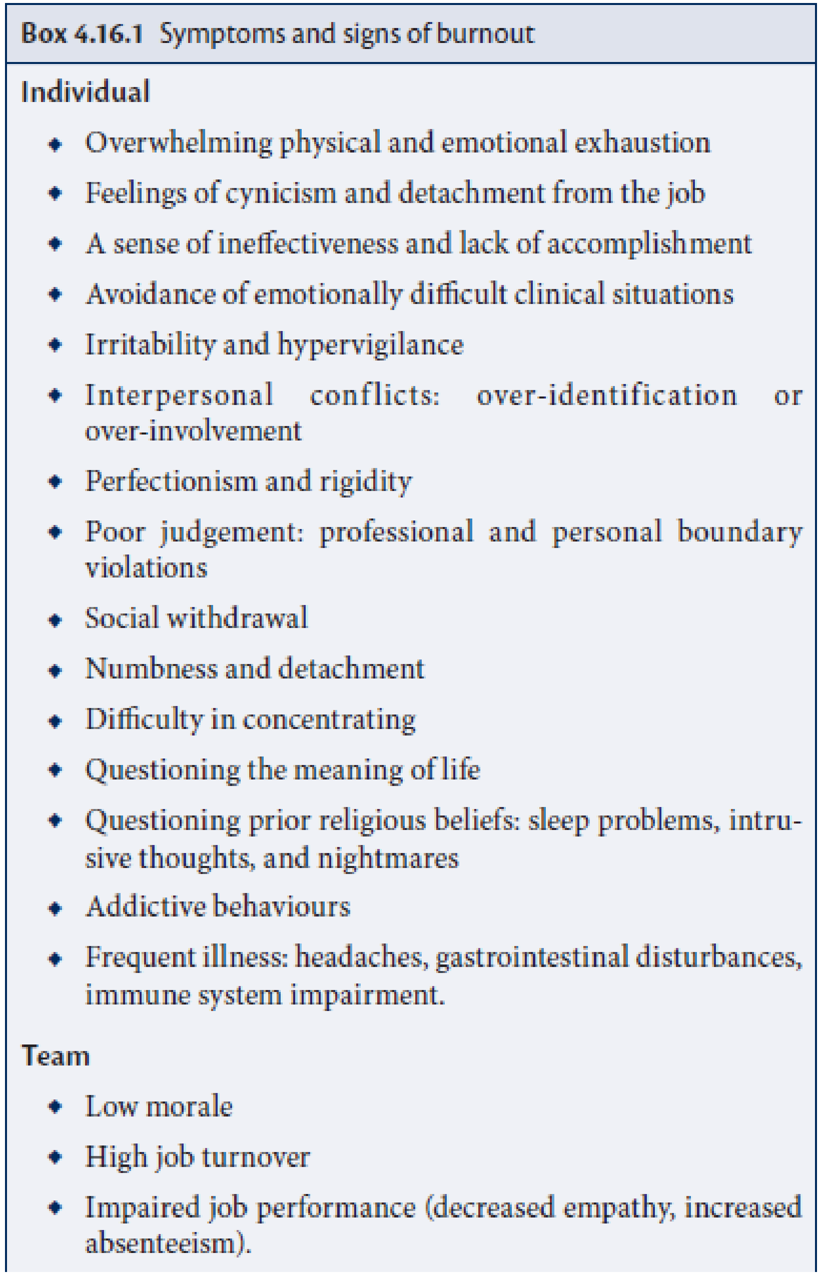


Fig. 4.16.1 The relationship between moral distress, compassion fatigue, and burnout.

In Textbook of Palliative Medicine (5th ed.)



Box 4.16.1 Symptoms and signs of burnout

Individual

- Overwhelming physical and emotional exhaustion
- Feelings of cynicism and detachment from the job
- A sense of ineffectiveness and lack of accomplishment
- Avoidance of emotionally difficult clinical situations
- Irritability and hypervigilance
- Interpersonal conflicts: over-identification or over-involvement
- Perfectionism and rigidity
- Poor judgement: professional and personal boundary violations
- Social withdrawal
- Numbness and detachment
- Difficulty in concentrating
- Questioning the meaning of life
- Questioning prior religious beliefs: sleep problems, intrusive thoughts, and nightmares
- Addictive behaviours
- Frequent illness: headaches, gastrointestinal disturbances, immune system impairment.

Team

- Low morale
- High job turnover
- Impaired job performance (decreased empathy, increased absenteeism).

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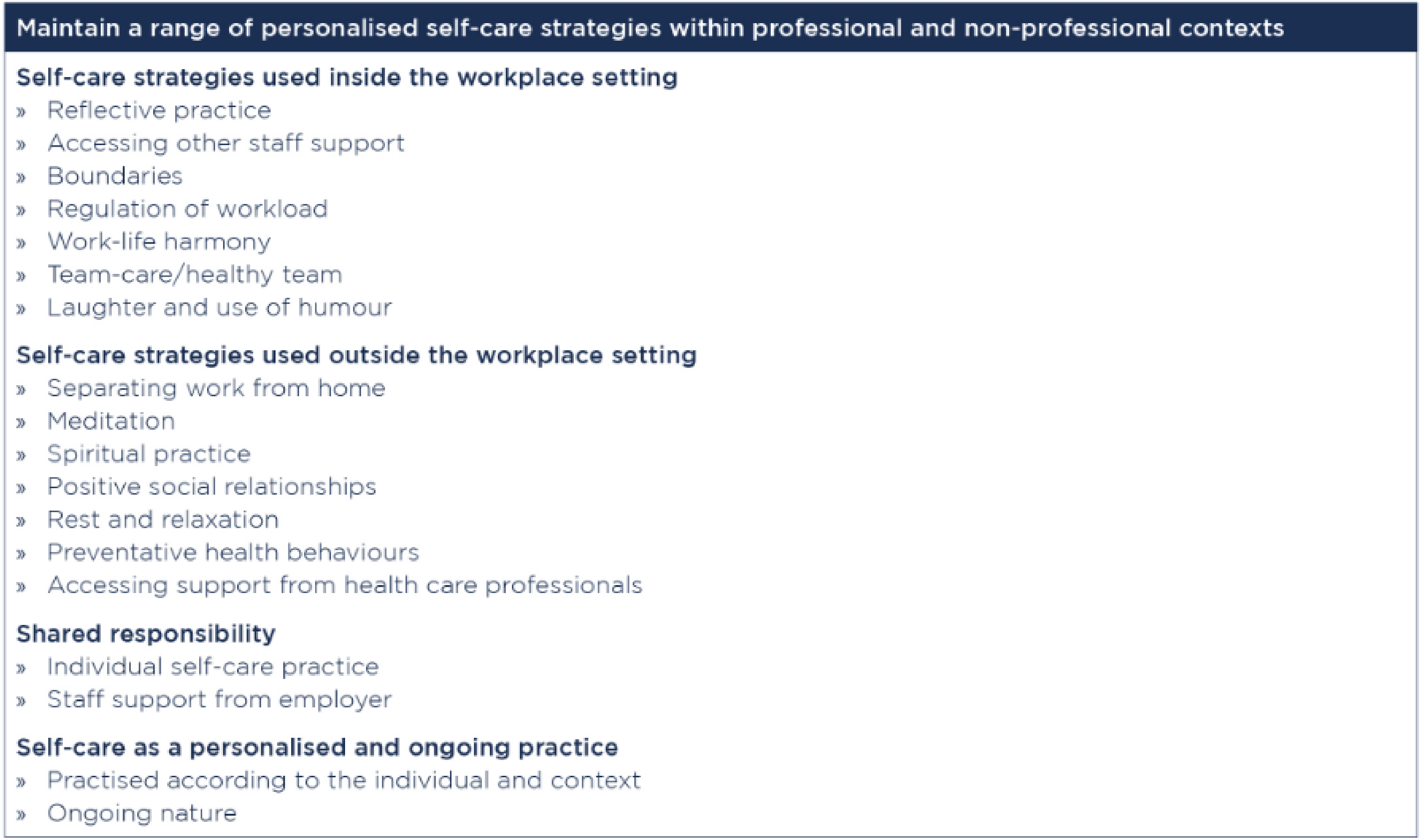
SELF-CARE

PHYSICAL

SOCIAL

INNER

← Personal contexts Professional contexts →



Maintain a range of personalised self-care strategies within professional and non-professional contexts

Self-care strategies used inside the workplace setting

- Reflective practice
- Accessing other staff support
- Boundaries
- Regulation of workload
- Work-life harmony
- Team-care/healthy team
- Laughter and use of humour

Self-care strategies used outside the workplace setting

- Separating work from home
- Meditation
- Spiritual practice
- Positive social relationships
- Rest and relaxation
- Preventative health behaviours
- Accessing support from health care professionals

Shared responsibility

- Individual self-care practice
- Staff support from employer

Self-care as a personalised and ongoing practice

- Practised according to the individual and context
- Ongoing nature

https://palliativecare.org.au/resource/resources-self-care-matters-practising-self-care/

Manage barriers and enablers to self-care practice

Facilitators of self-care

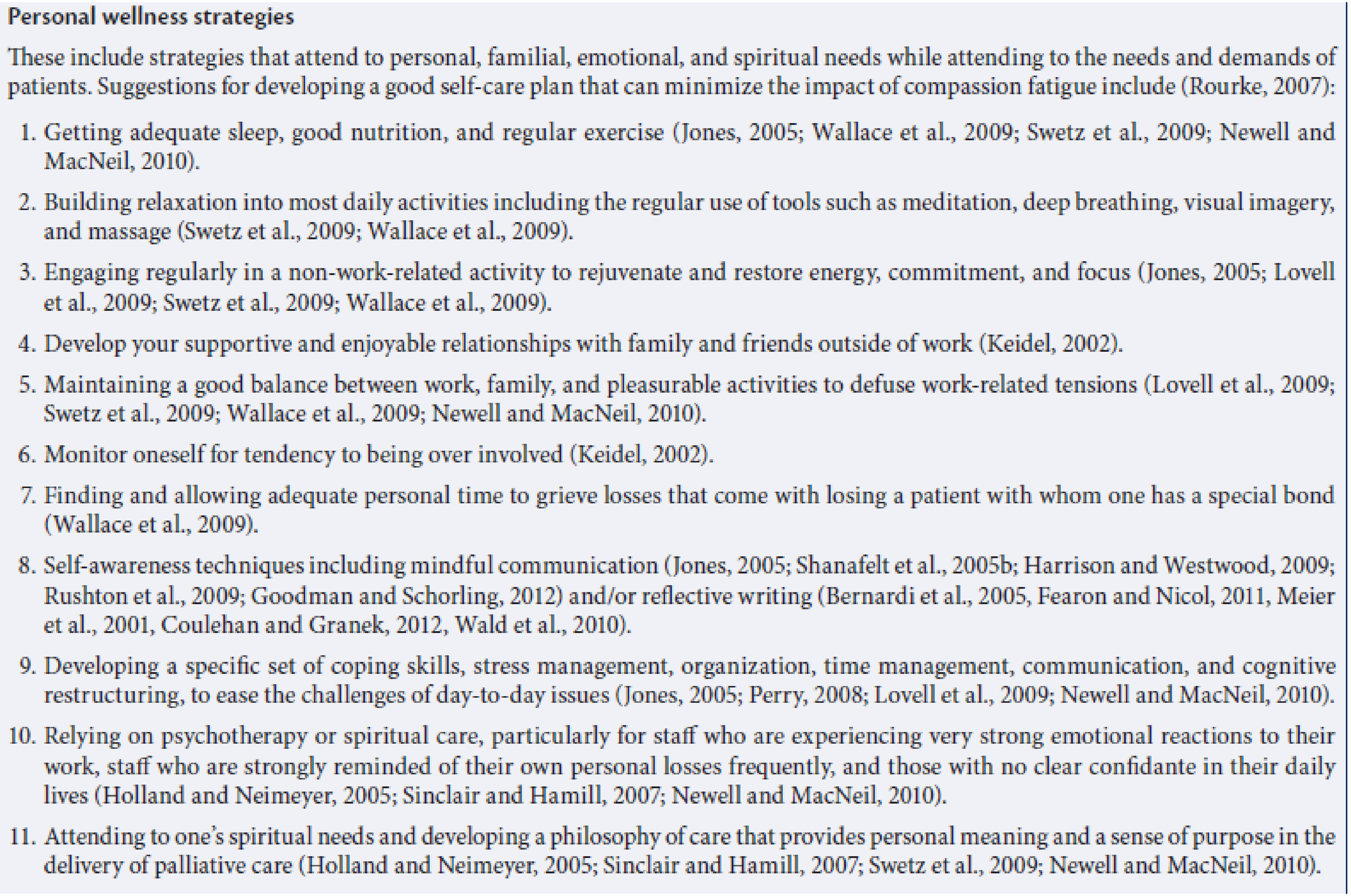
- Recognising importance of self-care
- Planning and prioritising self-care in a preventative approach
- Self-awareness
- Supportive work culture and leadership
- Leadership/role models to normalise self-care
- Positive emotions and relationships
- Character strengths

Impediments to self-care

- Unsupportive work culture and environment
- Stigma
- Busyness
- Lack of planning/prioritising self-care
- Inadequate boundaries between work and home
- Self-criticism and low self-worth

https://palliativecare.org.au/resource/resources-self-care-matters-practising-self-care/

PERSONAL STRATEGIES



Personal wellness strategies

These include strategies that attend to personal, familial, emotional, and spiritual needs while attending to the needs and demands of patients. Suggestions for developing a good self-care plan that can minimize the impact of compassion fatigue include (Rourke, 2007):

1. Getting adequate sleep, good nutrition, and regular exercise (Jones, 2005; Wallace et al., 2009; Swetz et al., 2009; Newell and MacNeil, 2010).
2. Building relaxation into most daily activities including the regular use of tools such as meditation, deep breathing, visual imagery, and massage (Swetz et al., 2009; Wallace et al., 2009).
3. Engaging regularly in a non-work-related activity to rejuvenate and restore energy, commitment, and focus (Jones, 2005; Lovell et al., 2009; Swetz et al., 2009; Wallace et al., 2009).
4. Develop your supportive and enjoyable relationships with family and friends outside of work (Keidel, 2002).
5. Maintaining a good balance between work, family, and pleasurable activities to defuse work-related tensions (Lovell et al., 2009; Swetz et al., 2009; Wallace et al., 2009; Newell and MacNeil, 2010).
6. Monitor oneself for tendency to being over involved (Keidel, 2002).
7. Finding and allowing adequate personal time to grieve losses that come with losing a patient with whom one has a special bond (Wallace et al., 2009).
8. Self-awareness techniques including mindful communication (Jones, 2005; Shanafelt et al., 2005b; Harrison and Westwood, 2009; Rushton et al., 2009; Goodman and Schorling, 2012) and/or reflective writing (Bernardi et al., 2005, Fearon and Nicol, 2011, Meier et al., 2001, Coulehan and Granek, 2012, Wald et al., 2010).
9. Developing a specific set of coping skills, stress management, organization, time management, communication, and cognitive restructuring, to ease the challenges of day-to-day issues (Jones, 2005; Perry, 2008; Lovell et al., 2009; Newell and MacNeil, 2010).
10. Relying on psychotherapy or spiritual care, particularly for staff who are experiencing very strong emotional reactions to their work, staff who are strongly reminded of their own personal losses frequently, and those with no clear confidante in their daily lives (Holland and Neimeyer, 2005; Sinclair and Hamill, 2007; Newell and MacNeil, 2010).
11. Attending to one's spiritual needs and developing a philosophy of care that provides personal meaning and a sense of purpose in the delivery of palliative care (Holland and Neimeyer, 2005; Sinclair and Hamill, 2007; Swetz et al., 2009; Newell and MacNeil, 2010).

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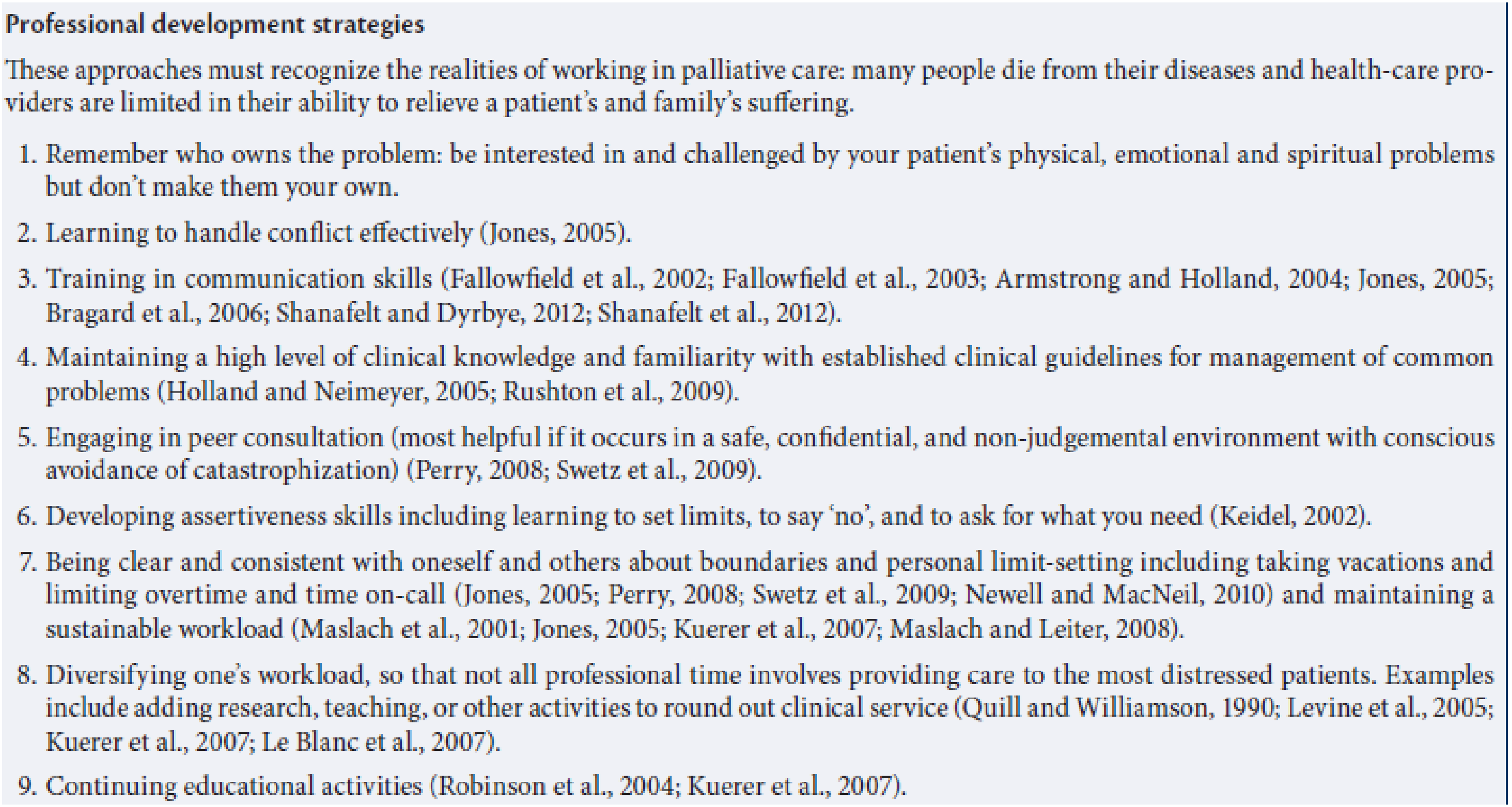
PROFESSIONAL STRATEGIES



Professional development strategies

These approaches must recognize the realities of working in palliative care: many people die from their diseases and health-care providers are limited in their ability to relieve a patient's and family's suffering.

1. Remember who owns the problem: be interested in and challenged by your patient's physical, emotional and spiritual problems but don't make them your own.
2. Learning to handle conflict effectively (Jones, 2005).
3. Training in communication skills (Fallowfield et al., 2002; Fallowfield et al., 2003; Armstrong and Holland, 2004; Jones, 2005; Bragard et al., 2006; Shanafelt and Dyrbye, 2012; Shanafelt et al., 2012).
4. Maintaining a high level of clinical knowledge and familiarity with established clinical guidelines for management of common problems (Holland and Neimeyer, 2005; Rushton et al., 2009).
5. Engaging in peer consultation (most helpful if it occurs in a safe, confidential, and non-judgemental environment with conscious avoidance of catastrophization) (Perry, 2008; Swetz et al., 2009).
6. Developing assertiveness skills including learning to set limits, to say 'no', and to ask for what you need (Keidel, 2002).
7. Being clear and consistent with oneself and others about boundaries and personal limit-setting including taking vacations and limiting overtime and time on-call (Jones, 2005; Perry, 2008; Swetz et al., 2009; Newell and MacNeil, 2010) and maintaining a sustainable workload (Maslach et al., 2001; Jones, 2005; Kuerer et al., 2007; Maslach and Leiter, 2008).
8. Diversifying one's workload, so that not all professional time involves providing care to the most distressed patients. Examples include adding research, teaching, or other activities to round out clinical service (Quill and Williamson, 1990; Levine et al., 2005; Kuerer et al., 2007; Le Blanc et al., 2007).
9. Continuing educational activities (Robinson et al., 2004; Kuerer et al., 2007).

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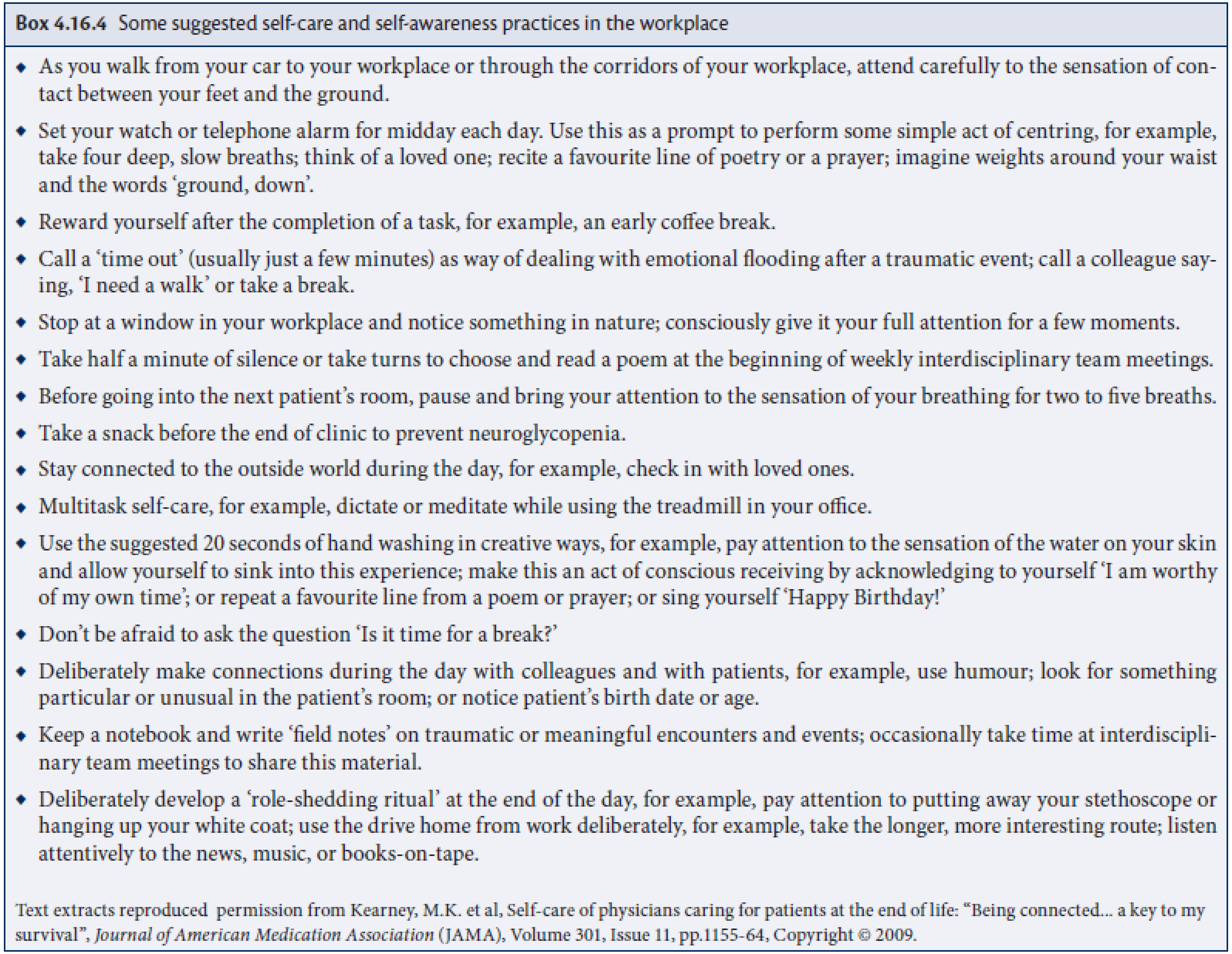
WORKPLACE



Box 4.16.4 Some suggested self-care and self-awareness practices in the workplace

- As you walk from your car to your workplace or through the corridors of your workplace, attend carefully to the sensation of contact between your feet and the ground.
- Set your watch or telephone alarm for midday each day. Use this as a prompt to perform some simple act of centring, for example, take four deep, slow breaths; think of a loved one; recite a favourite line of poetry or a prayer; imagine weights around your waist and the words 'ground, down'.
- Reward yourself after the completion of a task, for example, an early coffee break.
- Call a 'time out' (usually just a few minutes) as way of dealing with emotional flooding after a traumatic event; call a colleague saying, 'I need a walk' or take a break.
- Stop at a window in your workplace and notice something in nature; consciously give it your full attention for a few moments.
- Take half a minute of silence or take turns to choose and read a poem at the beginning of weekly interdisciplinary team meetings.
- Before going into the next patient's room, pause and bring your attention to the sensation of your breathing for two to five breaths.
- Take a snack before the end of clinic to prevent neuroglycopenia.
- Stay connected to the outside world during the day, for example, check in with loved ones.
- Multitask self-care, for example, dictate or meditate while using the treadmill in your office.
- Use the suggested 20 seconds of hand washing in creative ways, for example, pay attention to the sensation of the water on your skin and allow yourself to sink into this experience; make this an act of conscious receiving by acknowledging to yourself 'I am worthy of my own time'; or repeat a favourite line from a poem or prayer; or sing yourself 'Happy Birthday!'
- Don't be afraid to ask the question 'Is it time for a break?'
- Deliberately make connections during the day with colleagues and with patients, for example, use humour; look for something particular or unusual in the patient's room; or notice patient's birth date or age.
- Keep a notebook and write 'field notes' on traumatic or meaningful encounters and events; occasionally take time at interdisciplinary team meetings to share this material.
- Deliberately develop a 'role-shedding ritual' at the end of the day, for example, pay attention to putting away your stethoscope or hanging up your white coat; use the drive home from work deliberately, for example, take the longer, more interesting route; listen attentively to the news, music, or books-on-tape.

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SELF-CARE IS HOW YOU TAKE YOUR POWER BACK

GIVINGCARE
Empowering Caregivers

Thank you!

Teachers's name

Teachers e-mail

Date of the session