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Programa Académico Sobre Cuidados Paliativos en el Anciano

Calidad de muerte

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Calidad de muerte

- Para preservar la vida, requerimos conocer qué significa "vida" para cada individuo y salvaguardar la expresión de esta experiencia.

- Los pacientes con cáncer avanzado que han conversado con sus médicos sobre el final de la vida parecen tener mejor calidad de vida en sus últimos días y pagan menos por su cuidado.

•Strada, Alessandra. Preserving life at the end of life: Shifting the temporal dimension of hope. Palliative and Supportive Care. 2008; 6, 187-188

•Thompson, G;Chochinov, Harvey. Reducing the potential for suffering in older adults with advanced cancer. Palliative and Soporting Care. 2010; 8, 83-93.

•Prigerson , Holly. Health Care Cost in the Last Week of Life.Archive of Internal Medicine . 2009

Bienestar psicológico

- El temor a lo desconocido crea ansiedad; que es más desconocido que lo que ocurre después de la muerte?
- La aceptación a la muerte es variable en el contexto de la vida que han vivido.
- La depresión afecta aproximadamente a 1 de cada 4 pacientes que reciben cuidados paliativos.
- Los adultos mayores tienen menor ansiedad, depresión o distres emocional ante el diagnóstico de cáncer que los jóvenes.

•Matzo,Marianne; &Miller, David. Humor and death: A qualitie study of The New York cartoons (1986-2006). Palliative and Supportive Care. 2009;7. 487-493.

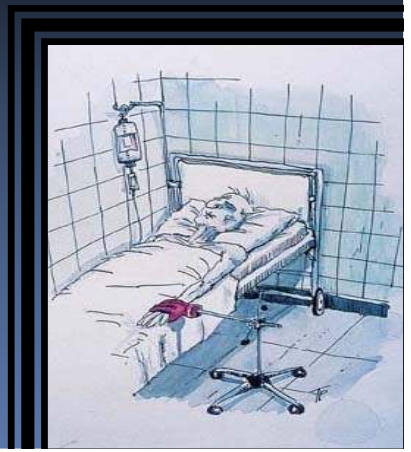
•Thompson, G;Chochinov, Harvey. Reducing the potential for suffering in older adults with advanced cancer. Palliative and Soporting Care. 2010; 8, 83-93.

Bienestar social

- La presencia de soporte social y redes de apoyo social han mostrado tener influencia positiva en la calidad de vida.
- Para interactuar con los familiares/amigos se requiere:
  - Control de síntomas
  - Atmósfera que promueva la comunicación
  - Claridad mental (medicación sedativa)
- La lucidez que se presenta durante las últimas horas de vida puede proveer una oportunidad para poner "en orden la casa" y despedirnos.

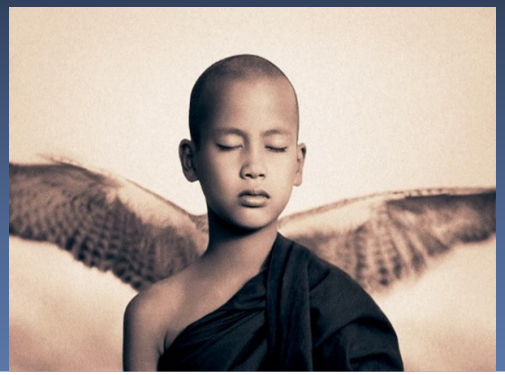
•Thompson, G;Chochinov, Harvey. Reducing the potential for suffering in older adults with advanced cancer. Palliative and Soporting Care. 2010; 8, 83-93.

Macleod, Sandy. Lightening up before death. Case Report. Palliative and Supportive Care. 2009; 7, 513-516



Bienestar espiritual

- Espiritualidad: aspiración profunda e íntima del ser humano a una visión de la vida y la realidad que integre, conecte, trascienda y dé sentido a la existencia.
- La búsqueda personal de sentido, conexión y trascendencia aflora especialmente en forma de necesidad, insatisfacción e incluso sufrimiento en el entorno del final de la vida.
- Mako et al. (2006) reportó que cerca del 96% de los pacientes con cáncer avanzado experimentan dolor espiritual durante su vida
- Cómo intervenir?
  - actitudes como la empatía compasiva y la humildad que nos otorga la ignorancia sobre el espacio interior del otro
  - la intención de acercamiento, libres del miedo que bloquea la capacidad de entendimiento
  - sólo se diagnostica aquello en lo que se piensa



• Benito E., Barbero J.(2008). Espiritualidad en Cuidados Paliativos: la dimensión emergente. Revista medicina paliativa, 15: 191-193

• Thompson, G;Chochinov, Harvey. Reducing the potential for suffering in older adults with advanced cancer. Palliative and Soporting Care. 2010; 8, 83-93.

The Quality of Dying and Death

Sarah Hales, MD; Camilla Zimmermann, MD, MSc; Gary Rodin, MD

- Revisión de la literatura revela que la calidad del morir y de la muerte tiene una construcción multidimensional,con 7 dominios:
  1. Experiencia física
  2. Experiencia social
  3. Experiencia espiritual o existencial
  4. Naturaleza del cuidado
  5. Preparación para la muerte
  6. Circunstancias de la muerte
  7. Fin de la vida

- La calidad del morir y de la muerte está determinada subjetivamente por numerosos factores que están influenciados por el juicio, tipo y estadio de la enfermedad y el rol social y profesional en la experiencia de muerte .

Arch Intern Med. 2008;168(9):912-918

Algunas descripciones del buen morir

- Morir mientras duerme
- Súbito
- Quieto
- Sin dolor
- Con control de síntomas
- Rodeado de la familia
- Conflictos resueltos
- No prolongación inapropiada de la muerte
- Relación con los cuidadores
- En paz con Dios
- Localización
- Escenario de la muerte
- Control sobre el tratamiento
- Posibilidad de decir adios
- Poder decidir sobre el cuidado al final de la vida

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Table. Studies Defining the Quality of Dying and Death

Source	Setting	Population	Objective	Method	Results	Quality of Dying and Death Domains Identified[a]
Low and Payne,[3] 1996	United Kingdom; hospice	50 Hospice nurses and social workers	To investigate palliative care professionals' perception of a good and bad death	Self-report questionnaires	3 Main factors related to perception of a good death (lack of patient distress, patient control, and staff's supporting role) and 4 main factors related to perception of a bad death (negative effect of death on the family, patient's nonacceptance of death, not dealing with patients' fears, and the age of the dying patient)	All 7 domains
Payne et al,[4] 1996	United Kingdom; inpatient hospice	18 Hospice cancer inpatients and 20 hospice health care professionals	To compare concepts of a good death used by patients and staff in a palliative care unit	Semistructured interviews	Patient descriptions of a good death included dying in one's sleep, dying quietly, dying suddenly, dying with dignity, and being pain free; staff descriptions of a good death included adequate symptom control, family involvement, peacefulness, and lack of distress	Physical experience, social experience, spiritual or existential experience, and circumstances of death
Leichtentritt and Rettig,[5] 2000	Israel; community	26 Elderly people	To reach an inductive understanding of the meanings attributed by elderly people in Israel to a good death	Open-ended interviews	Good death based on 5 essential essences (physiologic, personal, interpersonal, social, and cultural domains of life); a good death incorporated past, present, and future periods and was underlined by the fundamental wish to	All 7 domains

Steinhauser et al,[6] 2000	United States; hospitals and hospice	75 Participants (physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members)	To gather descriptions of components of a good death from patients, families, and health care professionals	Focus group discussions and in-depth interviews	6 Major components of a good death: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person	All 7 domains
Braun and Zir,[7] 2001	United States; Christian churches	121 Clergy and congregants affiliated with Christian churches	To explore the meaning of a good death and potential roles for faith communities	Focus groups	Definitions of a good death: pain managed, no inappropriate prolongation of dying, family is present and supportive, conflicts are resolved, and spiritual or existential issues are addressed	Physical experience, social experience, spiritual or existential experience, nature of health care, and life closure and death preparation
Kristjanson et al,[8] 2001	Australia; inpatient palliative care unit	20 Palliative care nurses	To describe palliative care nurses' perceptions of a good and bad death	Semistructured interviews	Nurses' judgments about the quality of death determined by patient-related factors described as whole vs fragmented, family-related factors described as connected vs unraveled, team-related factors described as smooth vs off balance, illness-specific factors described as in control vs impossible, and attributes of the death scene described as release vs chaos	Physical experience, psychological experience, social experience, nature of health care, life closure and death preparation, and circumstances of death

Source	Setting	Population	Objective	Method	Results	Quality of Dying and Death Domains Identified[a]
Mak,[9] 2001	China; inpatient hospice	33 Hospice inpatients with terminal cancer	To gain an understanding of what it means to die a good death from the perspective of Chinese patients	Semistructured interviews	Awareness of dying the foremost essential element of a good death	Life closure and death preparation
Hanson et al,[10] 2002	United States; long-term care facilities	77 Nursing assistants, nurses, and physicians	To define a good death in a nursing home	Focus groups	3 Themes: highly individualized care based on continuity relationships with caregivers; effective teamwork by staff, physicians, and family; and comprehensive advance care planning	Nature of health care
Hopkinson and Hallett,[11] 2002	United Kingdom; acute care hospitals	28 Nurses	To explore nurses' understandings of a good death	Open-ended interviews	Shared understanding of a good death included time with patient, peace, comfort, dignity, expectation, and having someone present; also found individual understandings of a good death shaped by personal experience and religious beliefs that changed over time	All 7 domains
Masson,[12] 2002	United Kingdom; inpatient and outpatient hospice service	10 Hospice cancer patients and 10 relatives of deceased hospice cancer patients	To explore nonprofessional perceptions of a good death	Open-ended interviews	3 Frames of reference within which participants understood death and dying: an acknowledgment of tension and paradox, contextualization within the life lived, and an attitude of flexible realism	All 7 domains
Pierson et al,[13] 2002	United States; academic clinics, community clinics, and community agencies	35 Patients with advanced AIDS	To identify and describe domains that define a good vs a bad death	Open-ended interviews	12 Domains mentioned by at least 2 participants: symptoms, quality of life, people present, dying process, location, sense of resolution, patient control of treatment, issues of spirituality, death scene, physician-assisted suicide	Physical experience, psychological experience, spiritual or existential experience, nature of health care, life closure and death

Leichtentritt,[16] 2004	Israel; community	14 Young adults	To study the meanings that young people attribute to a good death	Participant essays and semistructured interviews	4 Themes associated with least undesirable death: time, manner, and place of death and importance of death being beneficial to others	All 7 domains
Vig and Pearlman,[17] 2004	United States; academic medical centers	26 Men with terminal heart disease or cancer	To learn how terminally ill men conceptualize good and bad deaths	Semistructured interviews	Common components of a good death included in sleep, quick, painless, without suffering, at peace with God, peaceful, and without knowledge of impending death; and common components of a bad death included painful, prolonged, dependent, suffering, burdening others, drowning or shortness of breath, and not right with God	All 7 domains
Hirai et al,[18] 2006	Japan; regional cancer institutes, both acute and palliative care settings	63 Participants, including patients with advanced cancer, family members, physicians, and nurses	To identify components of a Japanese good death	Semistructured interviews	17 Attributes of a good death: freedom from pain or symptoms, good family relationship, dying in favorite place or environment, good relationship with medical staff, not being a burden to others, maintaining dignity, completion of life, maintaining sense of control, fighting against cancer, maintaining hope, not prolonging life, contributing to others, control of future, not being aware of death, appreciating others, maintaining pride, and having faith	All 7 domains

- Naturaleza subjetiva
  - El aspecto más común identificado del buen morir:

    "libre de dolor y sufrimiento"
- Influencia de la cultura
- Influencia del tipo y el estadio de la enfermedad
  - En la medida que progresa la enfermedad puede cambiar los deseos y actitudes de los pacientes que están muriendo
    - Desafío para la familia y profesionales de la salud

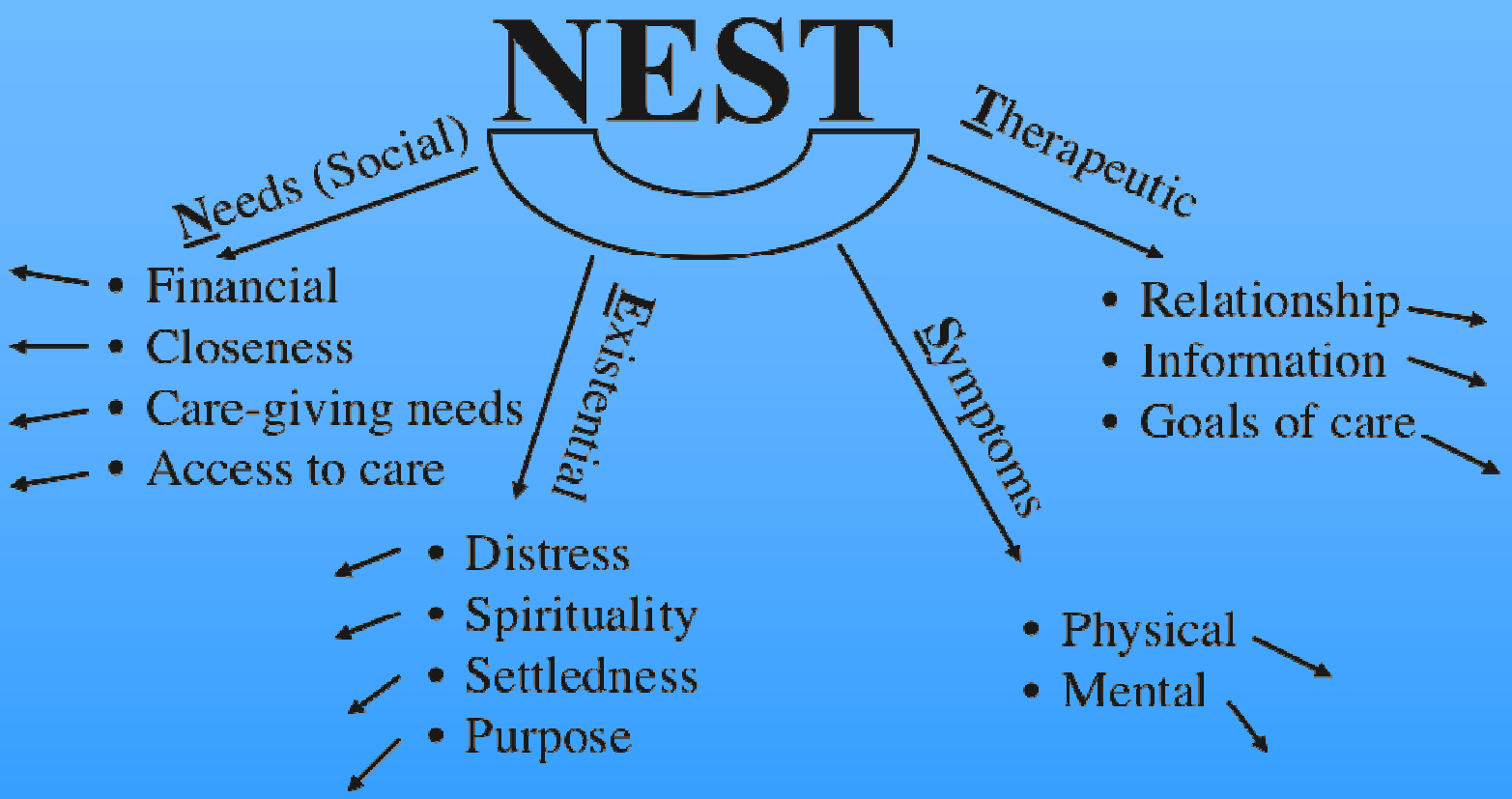


Fig. 1. Needs at the end-of-life screening tool (NEST).

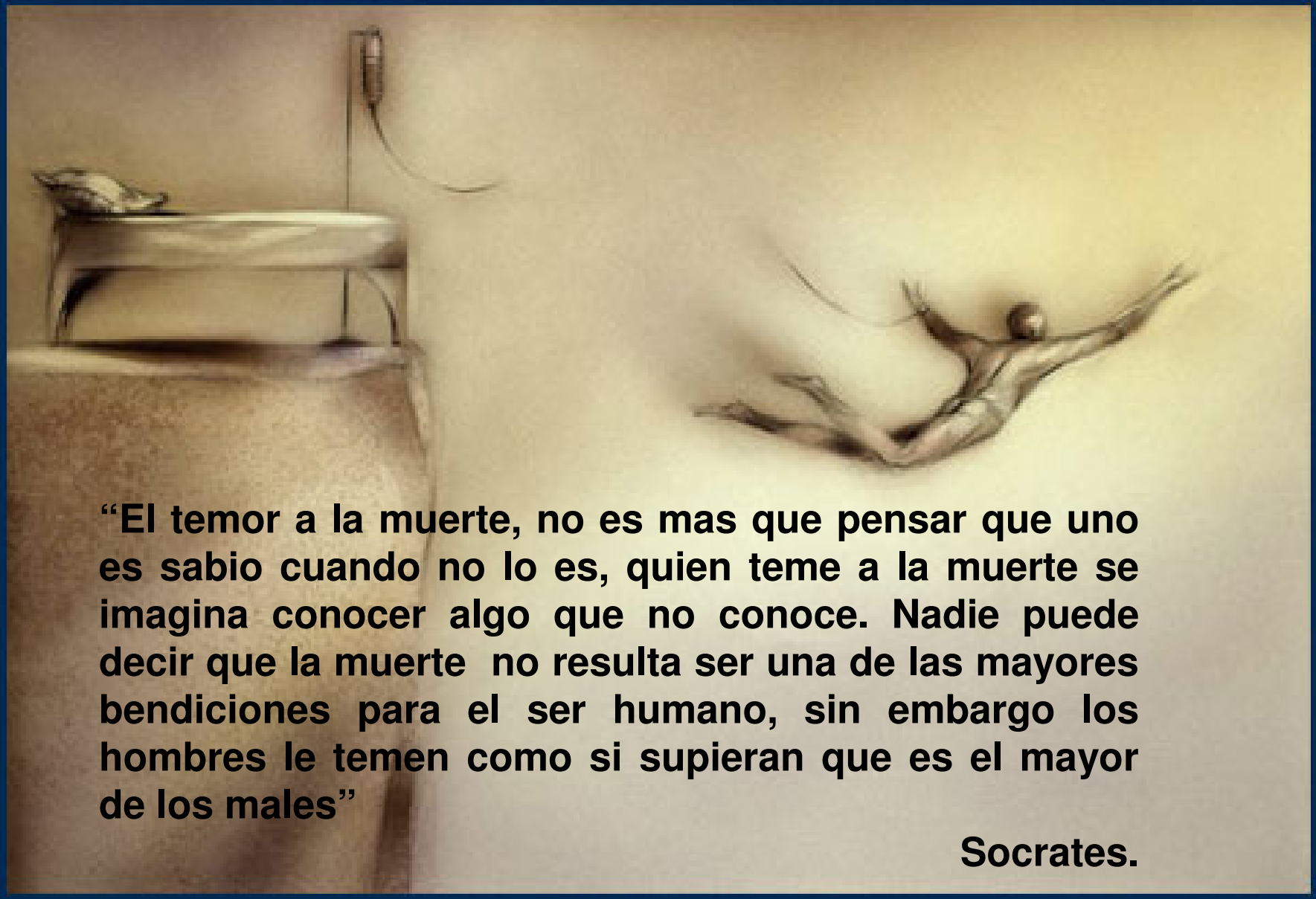
Clin Geriatr Med 20 (2004) 595–620

Desafíos

- La buena muerte es determinada subjetivamente y por lo tanto busca hablar de la verdad objetiva de la experiencia al final de la vida puede ser fútil

Conclusiones

- Buena muerte = muerte digna
- Manejo del dolor y otros síntomas
- Evitar la prolongación de la muerte y otras intervenciones innecesarias
- Estrechar las relaciones entre los familiares y amigos
- Mantener el control
- Aliviar la carga de los otros


“El temor a la muerte, no es mas que pensar que uno es sabio cuando no lo es, quien teme a la muerte se imagina conocer algo que no conoce. Nadie puede decir que la muerte no resulta ser una de las mayores bendiciones para el ser humano, sin embargo los hombres le temen como si supieran que es el mayor de los males”
Socrates.