UNIWERSYTET
MIKOŁAJA KOPERNIKA
W TORUNIU
Collegium Medicum w Bydgoszczy

1. Palliative Care – background, philosophy.
2. Care for the dying.

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Palliative Care – history, concept, models

Care for the dying.

History

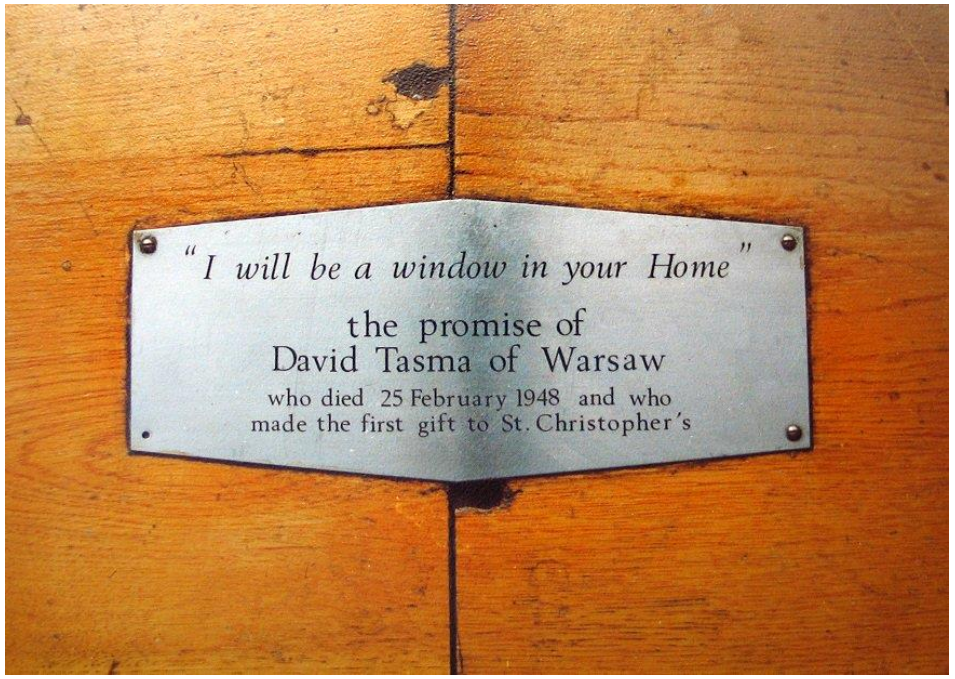
- Until the Renaissance Christian religious societies ran the earliest institutions called hospices, which cared for the ill, primarily people who became ill while traveling.
- Since XVI century the term *hospice* was reserved for dedicated places for the care of the incurably ill (and poor).
- The first time the term ***hospice*** was used to describe a place for the terminally ill was in 1842 in Lyon, France. The young widow and bereaved mother Madame Jeanne Garnier formed L'Association des Dames du Calvaire and is credited with establishing an institution there to care for the dying.
- In 1900 Irish Sisters of Charity founded St. Joseph's Convent in London and started visiting the sick in their homes. In 1902, they opened St. Joseph's Hospice in East London, with 30 beds for the dying poor.
- Cicely Saunders, then a young physician and previously trained as a nurse and social worker, worked from 1957 to 1967 at St. Joseph's Hospice, studying pain control in advanced cancer. This was the stimulus for her to establish St. Christopher's Hospice in London in 1967.

Cicely Saunders. Watch with Me. Inspiration for a ife in hospice care. Observatory Publications, 2005.

http://endoflifestudies.academicblogs.co.uk/open-access-to-watch-with-me-by-cicely-saunders/

„My soul is deeply grieved, to the point of death; remain here and keep **watch with Me”**„
Mt 26:38

"So, you men could not keep **watch with Me** for one hour?
Mt 26;40



„I only want what is in your mind and in your heart”

https://cicelysaundersarchive.wordpress.com/

Look at:

Close attention to his distress
It means really looking at him…
Learning what this pain is like *„from both sides*" and from this knowledge finding out how best to relieve it.

Learn:

What it feels like to be so ill, to be leaving life and its activity, to know… that you are parting from loves and responsibilities..
How to feel with patients without feeling like them

Make it possible for them:

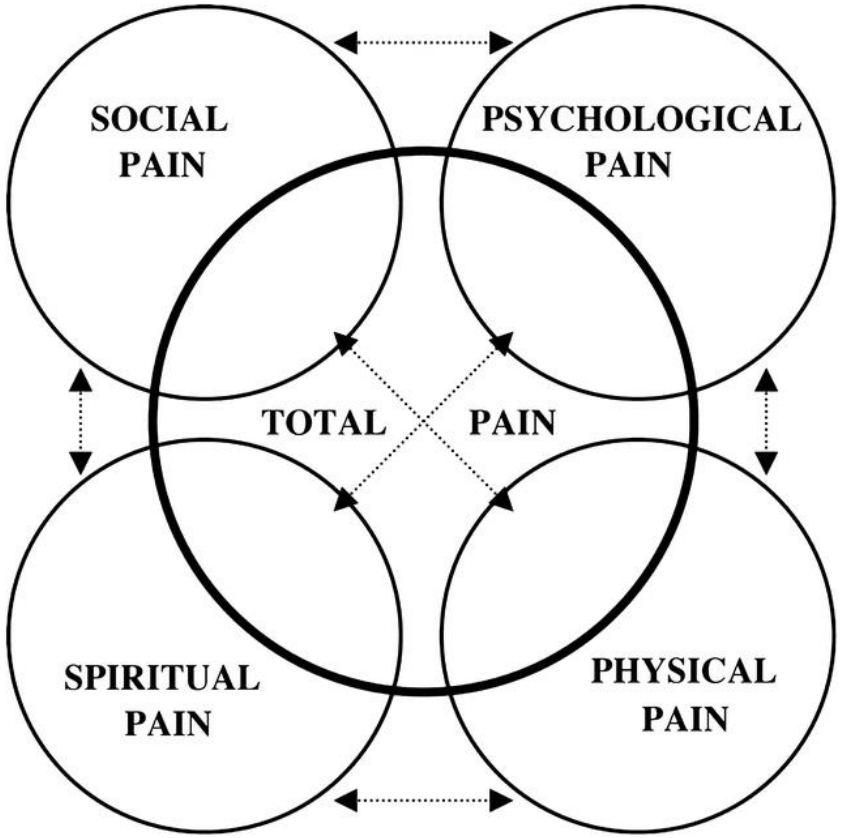
To pack their bags with the right things, with what they need
[*„My bags are packed and I am ready to go* …." St. Pope John XXIII].

To be there

„We should learn not only how to free patients from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen and how just to be there."

As we learn this we will also learn that the real work is not ours at all"

Total pain



https://hca.org.sg/HCA-Connect/223/Total-Pain-Its-Complicated

C. Saunders. The care of the dying patient and his family. Contact 1972(38):12-18.


SAINT
CHRISTOPHERS
HOSPICE

Dr Cicely Saunders (1918-2005)

History

- In 1974, Balfour Mount, a urologic surgeon, founded the world's first hospital-based palliative care service, at the Royal Victoria Hospital of McGill University in Montreal, Canada, as part of the teaching and research structure.

- It was Mount who first used the term ***palliative care***. Finally, in New York City, a consulting team began working throughout St. Luke's Hospital in 1974

Palliative Care

WHO definition [2002]
Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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.

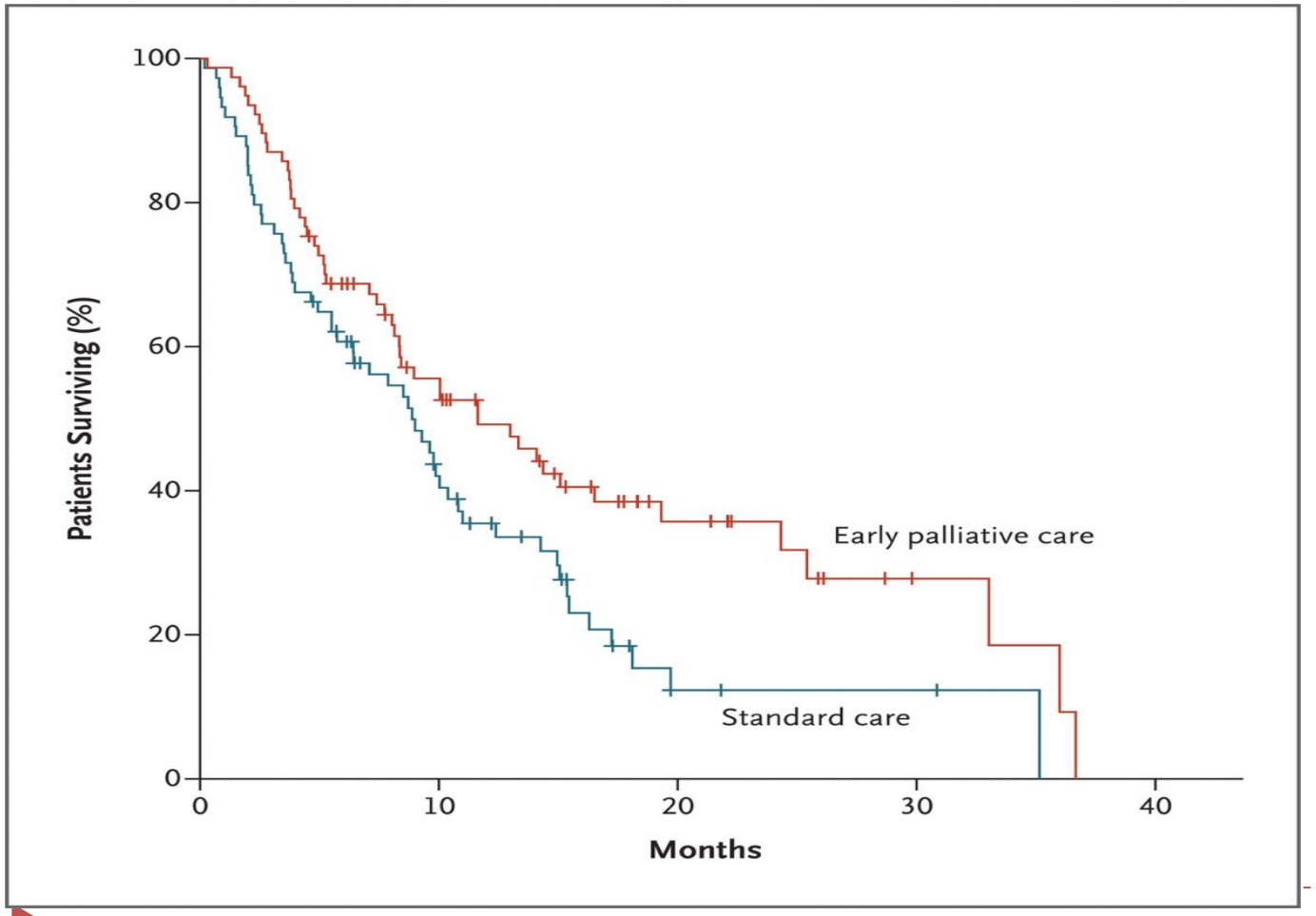
Center to Advance Palliative Care
Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.
Palliative care is provided by a specially trained team of palliative care physicians, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.
It is important to note that palliative care is based on needs, not prognosis

- **Affirms life and accept the dying/death as a natural process**
- **Intends neither to hasten or postpone death**

Specialistic palliative care (PC)

- Hospital based supportive PC team
- Out-patient clinic of Palliative Medicine
- Home care
- In-patient Departments/stationary hospice;
- Daycare centre;
- Bereavement support (out-patient clinic)

Temel et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *New England Journal of Medicine 2010; 363:733-742*



„Despite receiving less aggressive end-of-life care, patients in the palliative care group had significantly longer survival than those in the standard care group (median survival, 11.6 vs. 8.9 months; P=0.02)”

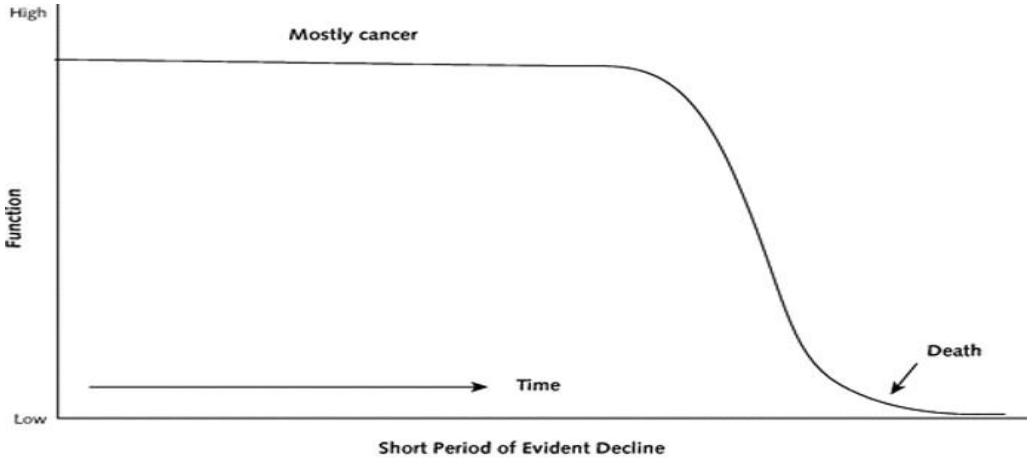
Palliative Care – history, concept, models

Care for the dying.

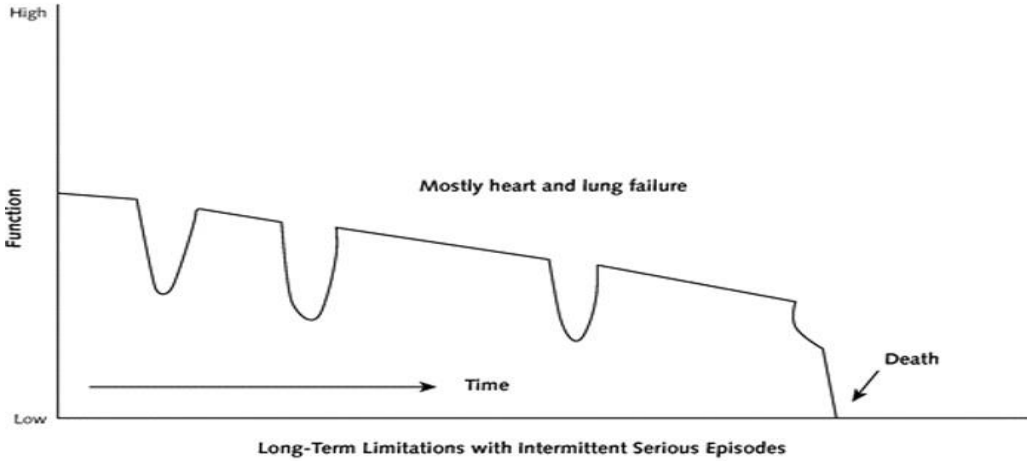
2 aims:

- **Quality of life (patient is living at this very moment)**

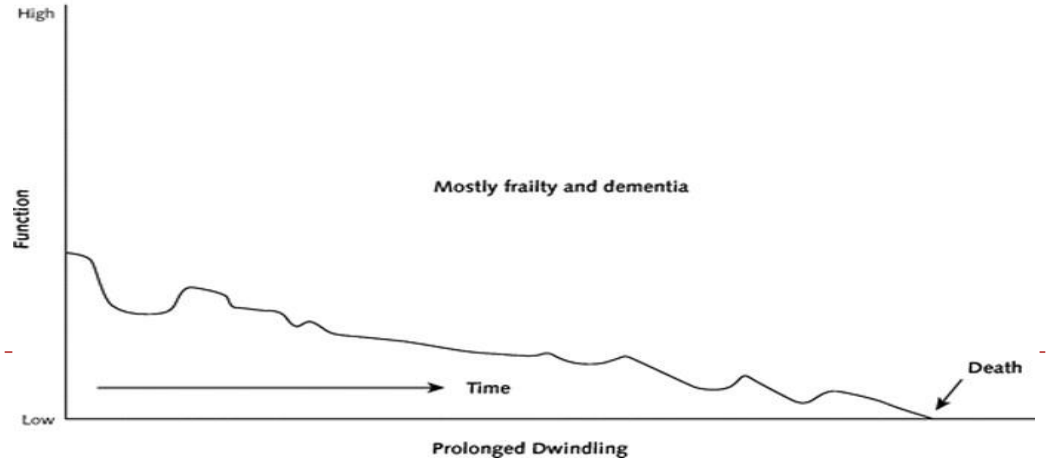
- **Preparation for death which is ahead**



Short Period of Evident Decline



Long-Term Limitations with Intermittent Serious Episodes



Prolonged Dwindling

Transitional phase in cancer patients (last weeks to days of life)

Decreased interest in surroundings; social withdrawal

Looking at own life history/completing tasks and unfinished business

↑weakness, fatigue

↓ appetite (interest may come and go)

More and more sleep

Sometimes: Falls/incontince/confusions

Last hours (days) in cancer patients….

- **Profound weakness, lying in the bed**
- **Difficulties in swallowing medication – no longer able to take tablets**
- **Diminished intake of food and fluids**
- **Drowsy; More and more sleep;**
- **Shorten periods of awareness; ↓ level of consiousness**
- **Nearing Death Awareness**
- **Incontinence….**

…as death approaches:

The *blood pressure* decreases; the pulse may increase or decrease.

The *body temperature* can fluctuate;

There is increased *perspiration* often with clamminess.

The *skin color* changes: flushed with fever, bluish with cold. A pale yellowish pallor (not to be confused with jaundice) often accompanies approaching death. Skin gets colder starting from the periphery and moving inward.

Breathing changes also occur. Respirations may increase, decrease or become irregular; periods of no breathing (apnea) are common.

***Congestion* will present as a rattling sound in the lungs and/or upper throat. This occurs because the patient is too weak to clear the throat or cough. The congestion can be affected by positioning, may be very loud, and sometimes just comes and goes.**

The *arms and legs* of the body may become cool to the touch. The hands and feet become purplish. The knees, ankles and elbows are blotchy. These symptoms are a result of decreased circulation.

The patient will enter a *coma* before death and not respond to verbal or tactile stimuli..

The pulse get weaker, blood pressure gradually falls. Eventually all signs of cardiac, respiratory and brainstem function cease.

Priorities for Care of the Dying Person

Duties and Responsibilities of Health and Care Staff

Published June 2014 by the
Leadership Alliance for the Care of Dying People

RECOGNISE	The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly. Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.
COMMUNICATE	Sensitive communication takes place between staff and the dying person, and those identified as important to them.
INVOLVE	The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
SUPPORT	The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
PLAN & DO	An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

If it is thought that a person may be entering the last days of life, gather and document information on:

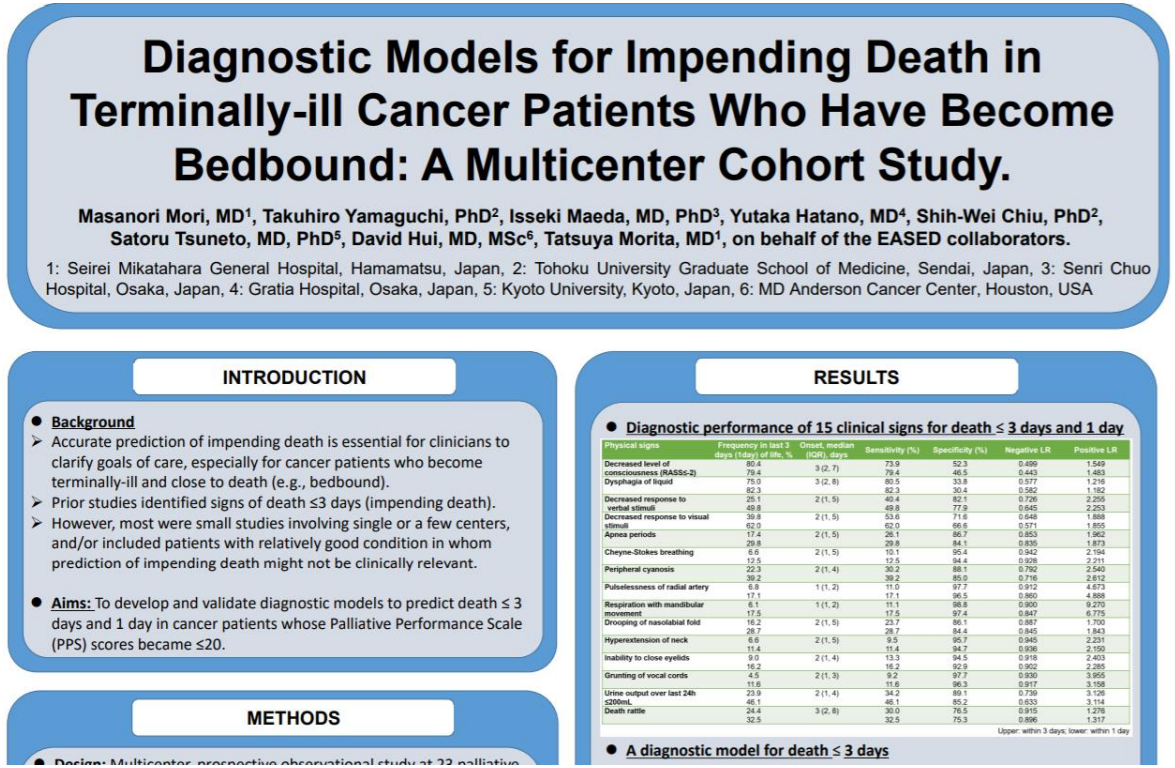
- the person's physiological, psychological, social and spiritual needs
- current clinical signs and symptoms
- medical history and the clinical context, including underlying diagnoses
- the person's goals and wishes
- the views of those important to the person about future care.

NICE guideline: Care for the dying in the last days of life Published 16 December 2015

How to recognize dying – diagnostic models?

Mori et al. Diagnostic models for impending death in terminally ill cancer patients: A multicenter cohort study. Cancer Med. 2021 Sep 29. doi: 10.1002/cam4.4314.

Masanori Mori et al. EAPC Congress online 2020



Diagnostic Models for Impending Death in Terminally-ill Cancer Patients Who Have Become Bedbound: A Multicenter Cohort Study.

Masanori Mori, MD[1], Takuhiro Yamaguchi, PhD[2], Isseki Maeda, MD, PhD[3], Yutaka Hatano, MD[4], Shih-Wei Chiu, PhD[2], Satoru Tsuneto, MD, PhD[5], David Hui, MD, MSc[6], Tatsuya Morita, MD[1], on behalf of the EASED collaborators.

1: Seirei Mikatahara General Hospital, Hamamatsu, Japan, 2: Tohoku University Graduate School of Medicine, Sendai, Japan, 3: Senri Chuo Hospital, Osaka, Japan, 4: Gratia Hospital, Osaka, Japan, 5: Kyoto University, Kyoto, Japan, 6: MD Anderson Cancer Center, Houston, USA

INTRODUCTION

- **Background**
  - Accurate prediction of impending death is essential for clinicians to clarify goals of care, especially for cancer patients who become terminally-ill and close to death (e.g., bedbound).
  - Prior studies identified signs of death ≤3 days (impending death).
  - However, most were small studies involving single or a few centers, and/or included patients with relatively good condition in whom prediction of impending death might not be clinically relevant.
- **Aims:** To develop and validate diagnostic models to predict death ≤ 3 days and 1 day in cancer patients whose Palliative Performance Scale (PPS) scores became ≤20.

METHODS

- **Design:** Multicenter, prospective observational study at 23 palliative

RESULTS

- **Diagnostic performance of 15 clinical signs for death ≤ 3 days and 1 day**

Physical signs	Frequency in last 3 days (1day) of life, %	Onset, median (IQR), days	Sensitivity (%)	Specificity (%)	Negative LR	Positive LR
Decreased level of consciousness (RASSs-2)	80.4 79.4	3 (2, 7)	73.9 79.4	52.3 46.5	0.499 0.443	1.549 1.483
Dysphagia of liquid	75.0 82.3	3 (2, 8)	80.5 82.3	33.8 30.4	0.577 0.582	1.216 1.182
Decreased response to verbal stimuli	25.1 49.8	2 (1, 5)	40.4 49.8	82.1 77.9	0.726 0.645	2.255 2.253
Decreased response to visual stimuli	39.8 62.0	2 (1, 5)	53.6 62.0	71.6 66.6	0.648 0.571	1.888 1.855
Apnea periods	17.4 29.8	2 (1, 5)	26.1 29.8	86.7 84.1	0.853 0.835	1.962 1.873
Cheyne-Stokes breathing	6.6 12.5	2 (1, 5)	10.1 12.5	95.4 94.4	0.942 0.926	2.194 2.211
Peripheral cyanosis	22.3 39.2	2 (1, 4)	30.2 39.2	88.1 85.0	0.792 0.716	2.540 2.612
Pulselessness of radial artery	6.8 17.1	1 (1, 2)	11.0 17.1	97.7 96.5	0.912 0.860	4.673 4.888
Respiration with mandibular movement	6.1 17.5	1 (1, 2)	11.1 17.5	98.8 97.4	0.900 0.847	9.270 6.775
Drooping of nasolabial fold	16.2 28.7	2 (1, 5)	23.7 28.7	86.1 84.4	0.887 0.845	1.700 1.843
Hyperextension of neck	6.6 11.4	2 (1, 5)	9.5 11.4	95.7 94.7	0.945 0.936	2.231 2.150
Inability to close eyelids	9.0 16.2	2 (1, 4)	13.3 16.2	94.5 92.9	0.918 0.902	2.403 2.285
Grunting of vocal cords	4.5 11.6	2 (1, 3)	9.2 11.6	97.7 96.3	0.930 0.917	3.955 3.158
Urine output over last 24h ≤200mL	23.9 46.1	2 (1, 4)	34.2 46.1	89.1 85.2	0.739 0.633	3.126 3.114
Death rattle	24.4 32.5	3 (2, 8)	30.0 32.5	76.5 75.3	0.915 0.896	1.276 1.317

Upper: within 3 days; lower: within 1 day

- **A diagnostic model for death ≤ 3 days**

15 symptoms related with the impending death, if Palliative Performance Scale (PPS)≤20 (i.e.bedbound, completely dependent)

Clinical characteristics	Prevalance (%)	
	3 days before death	1 day before death
↓ Level of conscioussness (Richmond Agitation Sedation Scale (RASS -2 to -5; light sedation = briefly awakens to voice (eyes open and contact <10sec)	67,2	79,4
Dysphagia of fluids	77,1	82,3
↓ response to verbal stimuli	29,4	49,8
↓ response to visual stimuli	43,9	62,0
Apnea periods (≥ 10s)	20,8	29,8
Cheyne-Stokesa breathing	8,4	12,5
Peripheral cyanosis	21,3	39,2
Pulselessness of radial artery	5,3	17,1
Respiration with mandibular movement (RMM)	4,8	17,5
Drooping of nasolabial fold	18,1	28,7
Hyperextension of neck	7,3	11,4
Inability to close eyelids	11,1	16,2
„Grunting" of vocal cords	6,1	11,6
↓urine output over last 24h (u/o) ≤200ml	22,4	46,1
Death rattle	26,2	32,5

Mori et al. 2020; 2021

PPS ≤20 (i.e., bedbound, completely dependent)

PPS - valid and reliable scale - 0% (death) to 100% (completely asymptomatic); includes the patient's function, oral intake, and cognitive status.

-PPS ≤20% signifies - patient is completely bedbound and has limited survival

Mori et al. Diagnostic models for impending death in terminally ill cancer patients: A multicenter cohort study. Cancer Med. 2021 Nov;10(22):7988-7995

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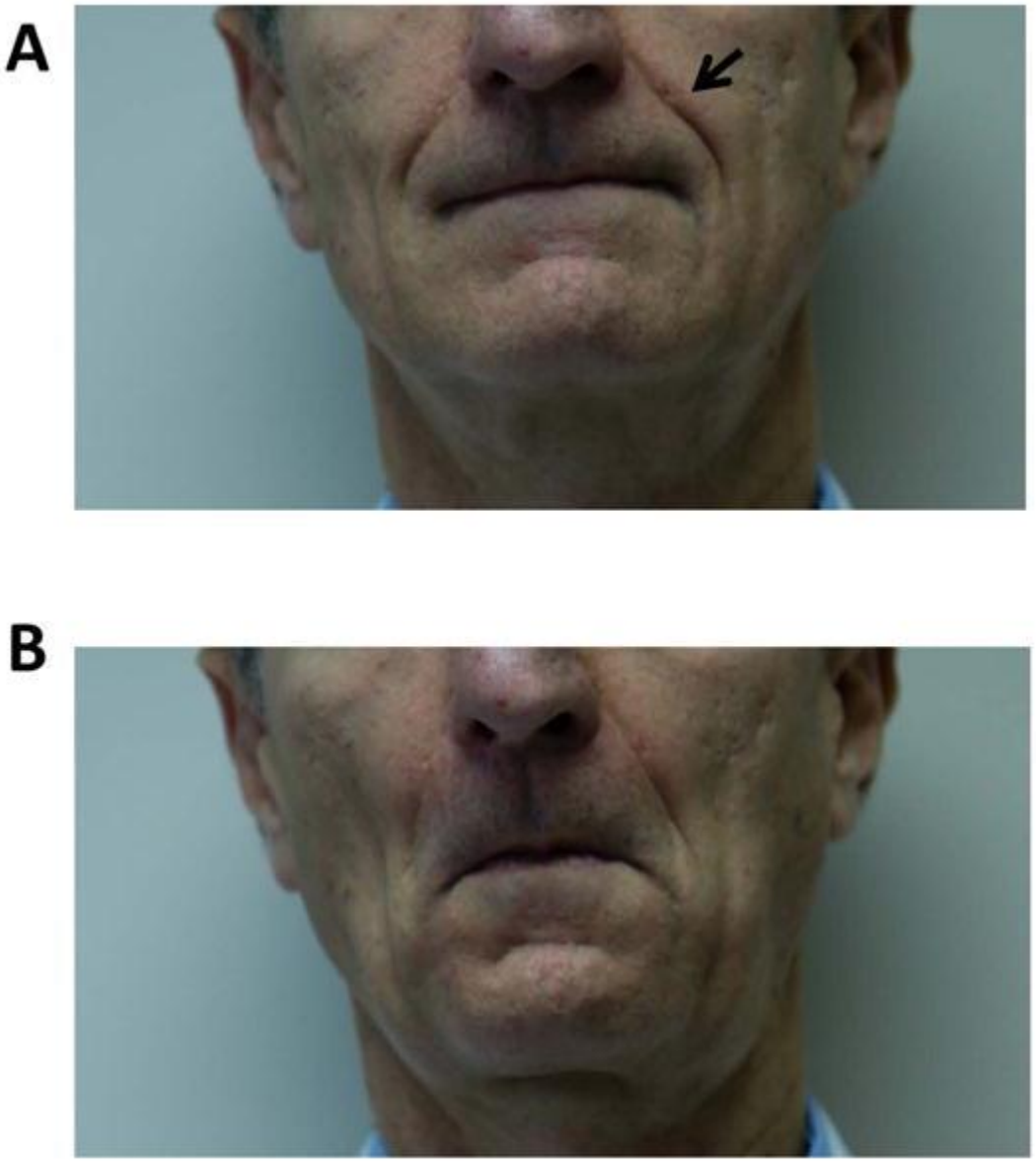
Mori et al. 2020; 2021



(A) Nasolabial folds are the skin folds that run from the nose to corners of the mouth (arrow). (B) In the last days of life, drooping of nasolabial fold may be noted in which they become less prominent because of the loss of facial muscle tone. The face appears to be more relaxed.

Hui D., Hess K., Dos Santos R. A diagnostic model for impending death in cancer patients: preliminary report. Cancer. 2015;121(21):3914–3921

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Symptom management

- **Proper assessment of symptoms and their causes**
- **Effective symptom management**
- **Optimal route of drug administration and dosage**
- **Regular treatment and „if needed”**
- **Individual plan (Including hydration? Comfort. Holistic support)**
- **Prevention of crisis**

Pharmacotherapy

NICE guideline: Care for the dying in the last days of life, 2015

1.When it is recognised that a person may be entering the last days of life, review their current medicines and, after discussion and agreement with the dying person and those important to them (as appropriate), stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm.

1.5.2 When involving the dying person and those important to them in making decisions about symptom control in the last days of life: • Use the dying person's individualised care plan to help decide which medicines are clinically appropriate. • Discuss the benefits and harms of any medicines offered.

1.5.3 When considering medicines for symptom control, take into account: • the likely cause of the symptom • the dying person's preferences alongside the benefits and harms of the medicine • any individual or cultural views that might affect their choice • any other medicines being taken to manage symptoms • any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.

1.5.4 Decide on the most effective route for administering medicines in the last days of life tailored to the dying person's condition, their ability to swallow safely and their preferences.

1.5.5 Consider prescribing different routes of administering medicine if the dying person is unable to take or tolerate oral medicines. Avoid giving intramuscular injections and give either subcutaneous or intravenous injections.

1.5.6 Consider using a syringe pump to deliver medicines for continuous symptom control if more than 2 or 3 doses of any 'as required' medicines have been given within 24 hours.

1.5.7 For people starting treatment who have not previously been given medicines for symptom management, start with the lowest effective dose and titrate as clinically indicated.

1.5.8 Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.

1.5.9 Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.

Symptom management

symptoms
pain
breathlessness
nausea
confusion
death rattle
dry mouth
incontinence

Pain in dying

- **Pains which appeared earlier before dying phase**

- **New pains due to:**
  - **Progression of disease**
  - **Change in medication/route of administration**
  - **Pathological fractures**
  - **Development of oral thrush**
  - **Urinary retention/constipation**
  - **Pressure ulcers**
  - **(Opioid) hyperalgesia**
  - **Spiritual or psychological suffering**

NICE guideline: Care for the dying in the last days of life, 2015

Managing pain

1.5.10. Consider non-pharmacological management of pain in a person in the last days of life.
1.5.11 Be aware that not all people in the last days of life experience pain. If pain is identified, manage it promptly and effectively, and treat any reversible causes of pain, such as urinary retention.
1.5.12 Assess the dying person's level of pain and assess for all possible causes when making prescribing decisions for managing pain.
1.5.13 Follow the principles of pain management used at other times when caring for people in the last days of life, for example, matching the medicine to the severity of pain and, when possible, using the dying person's preferences for how it is given.
1.5.14 For a person who is unable to effectively explain that they are in pain, for example someone with dementia or learning disabilities, use a validated behavioural pain assessment to inform their pain management.

NICE guideline: Care for the dying in the last days of life, 2015

Managing noisy respiratory secretions

1.5.29 Assess for the likely causes of noisy respiratory secretions in people in the last days of life *(exclude for example pulmonary oedema, as the treatment is different – lecturer's comment)*. Establish whether the noise has an impact on the dying person or those important to them. Reassure them that, although the noise can be distressing, it is unlikely to cause discomfort. Be prepared to talk about any fears or concerns they may have.

1.5.30 Consider non-pharmacological measures to manage noisy respiratory or pharyngeal secretions, to reduce any distress in people at the end of life *(1/ first of all – changing one's position – lying the patient on their side to facilitate postural drainage; 2/ consider whether trial with the gentle oropharyngeal suctioning could be helpful but if not causing more distress to the patient – lecturer's comment)*.

1.5.31 Consider a trial of medicine to treat noisy respiratory secretions if they are causing distress to the dying person. Tailor treatment to the dying person's individual needs or circumstances, using 1 of the following drugs:

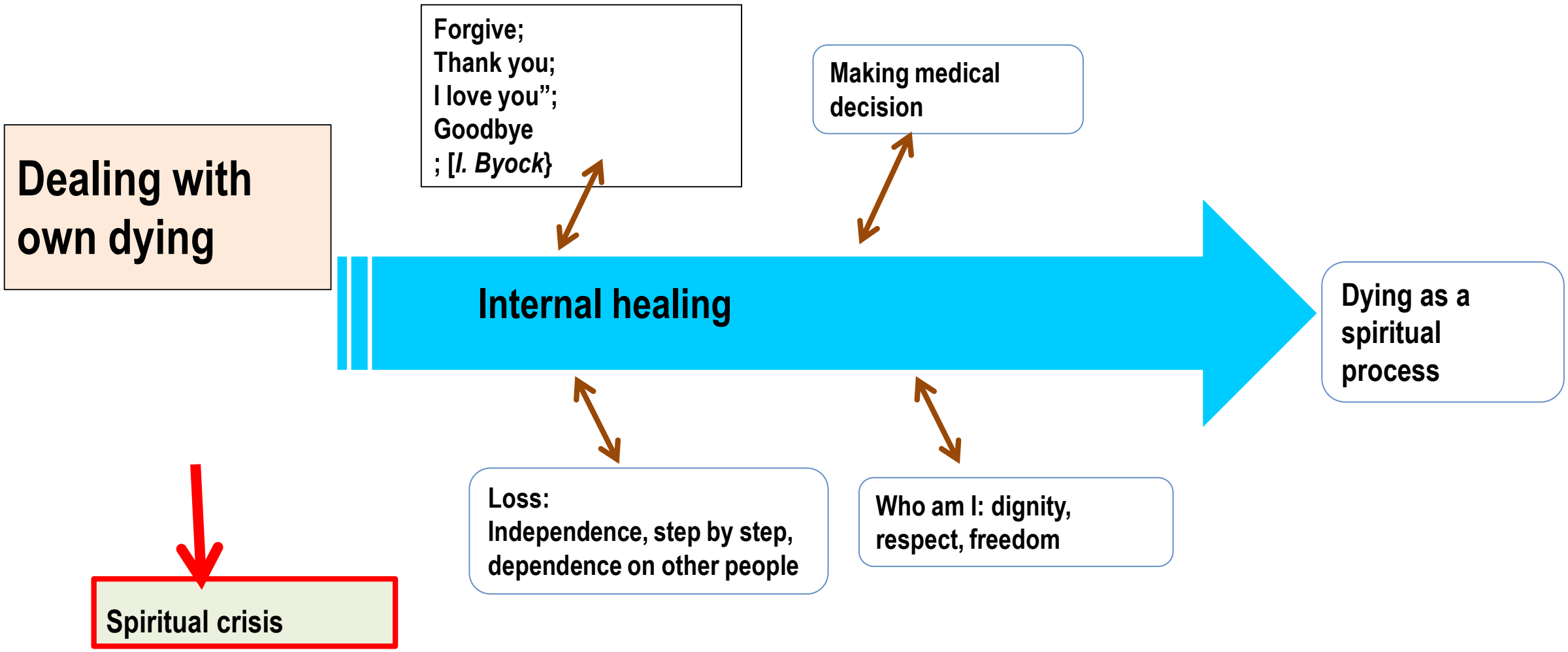
• atropine or • glycopyrronium bromide or • hyoscine butylbromide *(used for example in Poland – lecturer's comment*) or • hyoscine hydrobromide .

1.5.32 When giving medicine for noisy respiratory secretions: • Monitor for improvements, preferably every 4 hours, but at least every 12 hours. • Monitor regularly for side effects, particularly delirium, agitation or excessive sedation when using atropine or hyoscine hydrobromide. • Treat side effects, such as dry mouth, delirium or sedation.

1.5.33 Consider changing or stopping medicines if noisy respiratory secretions continue and are still causing distress after 12 hours (medicines may take up to 12 hours to become effective).

1.5.34 Consider changing or stopping medicines if unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation and unwanted levels of sedation, persist.

Spiritual care



Słyszy do końca..

Sci Rep. 2020 Jun 25;10(1):10336.

www.nature.com/scientificreports

SCIENTIFIC REPORTS

nature research

OPEN

Electrophysiological evidence of preserved hearing at the end of life

Elizabeth G. Blundon[1], Romayne E. Gallagher[2,4] & Lawrence M. Ward[1,3]✉

This study attempts to answer the question: "Is hearing the last to go?" We present evidence of hearing among unresponsive actively dying hospice patients. Individual ERP (MMN, P3a, and P3b) responses to deviations in auditory patterns are reported for conscious young, healthy control participants, as well as for hospice patients, both when the latter were conscious, and again when they became unresponsive to their environment. Whereas the MMN (and perhaps too the P3a) is considered an automatic response to auditory irregularities, the P3b is associated with conscious detection of oddball targets. All control participants, and most responsive hospice patients, evidenced a "local" effect (either a MMN, a P3a, or both) and some a "global" effect (P3b) to deviations in tone, or deviations in auditory pattern. Importantly, most unresponsive patients showed evidence of MMN responses to tone changes, and some showed a P3a or P3b response to either tone or pattern changes. Thus, their auditory systems were responding similarly to those of young, healthy controls just hours from end of life. Hearing may indeed be one of the last senses to lose function as humans die.

Blundon et al. Electrophysiological evidence of sustained attention to music among conscious participants and unresponsive hospice patients at the end of life. Clin Neurophysiol. 2022 Jul;139:9-22.

„Nearing death awareness" ; „Deathbed visions" (as a part of „End of life experiences" (ELEs)

CC 50-60% of dying

Callanan M & Kelley P, Final Gifts. New York, NY: Bantam Books; 1992

Fenwick P, Lovelace H, Brayne S. Arch Gerontol Geriatr 2010;51:173-179

Sarah Trumbull on Her Deathbed by John Trumbull , 1824, Yale University Art Gallery

NDA

Categories	Comments
Preparing for travel or change	
Describing a place	with a great sense of wonder. Apparently, it's quite a beautiful place, colours, music
Talking to or being in the presence of someone who is deceased	Contrary to hallucinasions, people who have NDA seem to be calmed and soothed by them. They appear to help the person to let go of the physical world and overcome their fear of dying.
Knowledge of when death will occur:	
Choosing the time of death	
Needing reconciliation	a desire to bring closure to their life as if there are unfinished business in their way holding them back

PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #118
NEAR DEATH AWARENESS

Adam Marks, MD, MPH and Lucille Marchand MD, BSN

Background Near death awareness (NDA) is a term to describe a dying person's experiences of the dying process and broadly refers to a variety of experiences such as end of life dreams or visions. Information comes from broadly reported anecdotes and several case series which suggest that up to 50-60% of patients will experience some form of NDA prior to their death(1). The language patients use to communicate NDA may be symbolic and if caretakers are not aware that NDA can occur, patients may be ignored, treated condescendingly, or inappropriately medicated for delirium. Family, friends, and health professionals may respond with annoyance, frustration or fear. This, in turn, may cause isolation, suffering, and impair the dying person's ability to communicate meaningful experiences at the end of life.

NDA vs. Delirium In studies engaging both patients and caregivers, NDA emerges as distinct from delirious states. In general, as opposed to hallucinations in delirious states, NDA occur in clear consciousness; they are reported with clarity, detail, and organization; and they often evoke feelings of comfort, rather than distress (2-3) See *Fast Facts* #1 for further information on delirium.

Impact of NDA on Existential Distress: NDA also differ from deathbed hallucinations with respect to their impact on patients. In her 2010 analysis of deathbed phenomena, Mazzarino-Willett found that NDA tends to be spiritually transformative, while hallucinations tend to be relatively insignificant (1). In addition, deaths including NDA are more frequently calm and peaceful than are deaths without such experiences (4).Thus NDA has been distinctly observed to affect positively the quality of the dying process.

Near Death Phenomena The recognition of NDA requires attentive listening. Health professionals, family, friends and caregivers can help decipher NDA messages. The content of NDA often will vary based on cultural background, but several common experiences relating to NDA have been described and include (5-6):

- Communicating with or experiencing the presence of someone who is not alive.
- Preparing for travel or a change.
- Describing a place they can see in another realm (i.e. heaven).
- Knowing when death will occur.

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Expanding the Understanding of Content of End-of-Life Dreams and Visions: A Consensual Qualitative Research Analysis

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Abstract

Background: Research has established End-of-Life Dreams and Visions (ELDVs) as prevalent, meaningful valid experiences that may help patients cope with illness and approaching death. However, no inductive qualitative analysis has explored the phenomenology of ELDVs from the perspective of hospice homecare patients.

Objective: The purpose of this study is to evaluate the content of ELDVs by using a rigorous qualitative approach.

Design: Five hundred forty-eight ELDVs were collected from weekly interviews of hospice homecare patients and analyzed by using Consensual Qualitative Research Methodology.

Settings/Subject: Participants were enrolled in a county-wide hospice homecare program between January 2013–March 2015.

Results: The following domains emerged: (1) Interpersonal, (2) Affective Experience and Reflection, (3) Activities, and (4) Setting/Location.

Conclusions: This study suggests that ELDV content may include a broader spectrum of experiences that reflect waking life than previously believed. Clinical implications suggest that it may be important for providers to engage with ELDVs, as they are psychologically significant experiences that may be a source of clinical insight.

Patient name:
Hospital No:
NHS No.
D.O.B:

or affix patient ID sticker here

Brighton and Sussex University Hospitals NHS
NHS Trust

HAVE YOU RECOGNISED YOUR PATIENT MAY DIE IN THE COMING HOURS OR DAYS?

ENSURE YOU:

- HAVE CONSIDERED POTENTIALLY REVERSIBLE CAUSES WHICH MAY BE APPROPRIATELY TREATED
- HAVE COMMUNICATED WITH THE PATIENT AND THOSE IMPORTANT TO THEM
- AIM TO INVOLVE A SENIOR DECISION MAKER (SpR/CONSULTANT)
- DOCUMENT CPR STATUS AND TREATMENT ESCALATION PLAN
- ASSESS SYMPTOMS AND PRESCRIBE APPROPRIATE MEDICATION
- ASSESS NEED FOR CLINICALLY ASSISTED HYDRATION AND NUTRITION
- CONSIDER IF DISCHARGE IS FEASIBLE IF PREFERRED PLACE OF CARE IS HOME
- CONSULT 'PALLIATIVE CARE' TAB ON TRUST INTRANET FOR FURTHER GUIDANCE

THEN:

DOCTORS

COMPLETE INDIVIDUALISED CARE PLAN (ICP) FOR THE DYING PATIENT OVERLEAF

NURSES

ONCE ICP COMPLETED USE SYMPTOM OBSERVATION CHART & DAILY CARE PLAN FOR THE DYING PATIENT

DOCTOR
NAME: _____ GRADE _____
SIGNATURE: _____ BLEEP _____
DATE : __/__/_____ TIME ___:___

NURSE
NAME: _____ GRADE _____
SIGNATURE: _____
DATE : __/__/_____ TIME ___:___

FURTHER GUIDANCE IS AVAILABLE ON PALLIATIVE CARE INTRANET PAGE AND VIA MICROGUIDE APP

HAVE YOU RECOGNISED YOUR PATIENT MAY DIE IN THE COMING HOURS OR DAYS?

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Symptom Observation Chart for the Dying Patient

Brighton and Sussex University Hospitals NHS Trust

Patient name:
Hospital No:
NHS No.
D.O.B:
or affix patient ID sticker here

Date patient was recognised as dying: ___/___/_____

Record observations at least 4 hourly

Month / Year	Date / Time																								Date / Time
Pain (reported or observed)	3													3												3
	2													2												2
	1													1												1
	0													0												0
Nausea	3													3												3
	2													2												2
	1													1												1
	0													0												0
Vomiting	3													3												3
	2													2												2
	1													1												1
	0													0												0
Breathless-ness	3													3												3
	2													2												2
	1													1												1
	0													0												0
Respiratory Secretions	3													3												3
	2													2												2
	1													1												1
	0													0												0
Agitation/ Distress	3													3												3
	2													2												2
	1													1												1
	0													0												0
Other, if present (state) _____	3													3												3
	2													2												2
	1													1												1
	0													0												0
Mouthcare - confirm given																										
HCA signature																										HCA
Registered nurse signature																										Reg Nurse
Doctor signature																										Doctor

3 = Symptom present, does not resolve with PRN medication	Urgent doctor review of patient and care plan is required for any single symptom score of 3
2 = Symptom present, requires PRN medication to resolve	Care plan continues. If 3 consecutive symptom scores of 2 are present (for any symptom), urgent doctor review of patient and care plan is required
1 = Symptom present, resolved without PRN medication	Care plan continues, consider if adaptions may be required
0 = Symptom absent	Care plan continues

v8 Approved by BSUH Health Records Committee September 2014, v9 updated May2017
WGN 500573 05/17

DAILY NURSING CARE PLAN FOR THE DYING PERSON

Patient name:
Hospital No:
NHS No.
D.O.B:
or affix patient ID sticker here

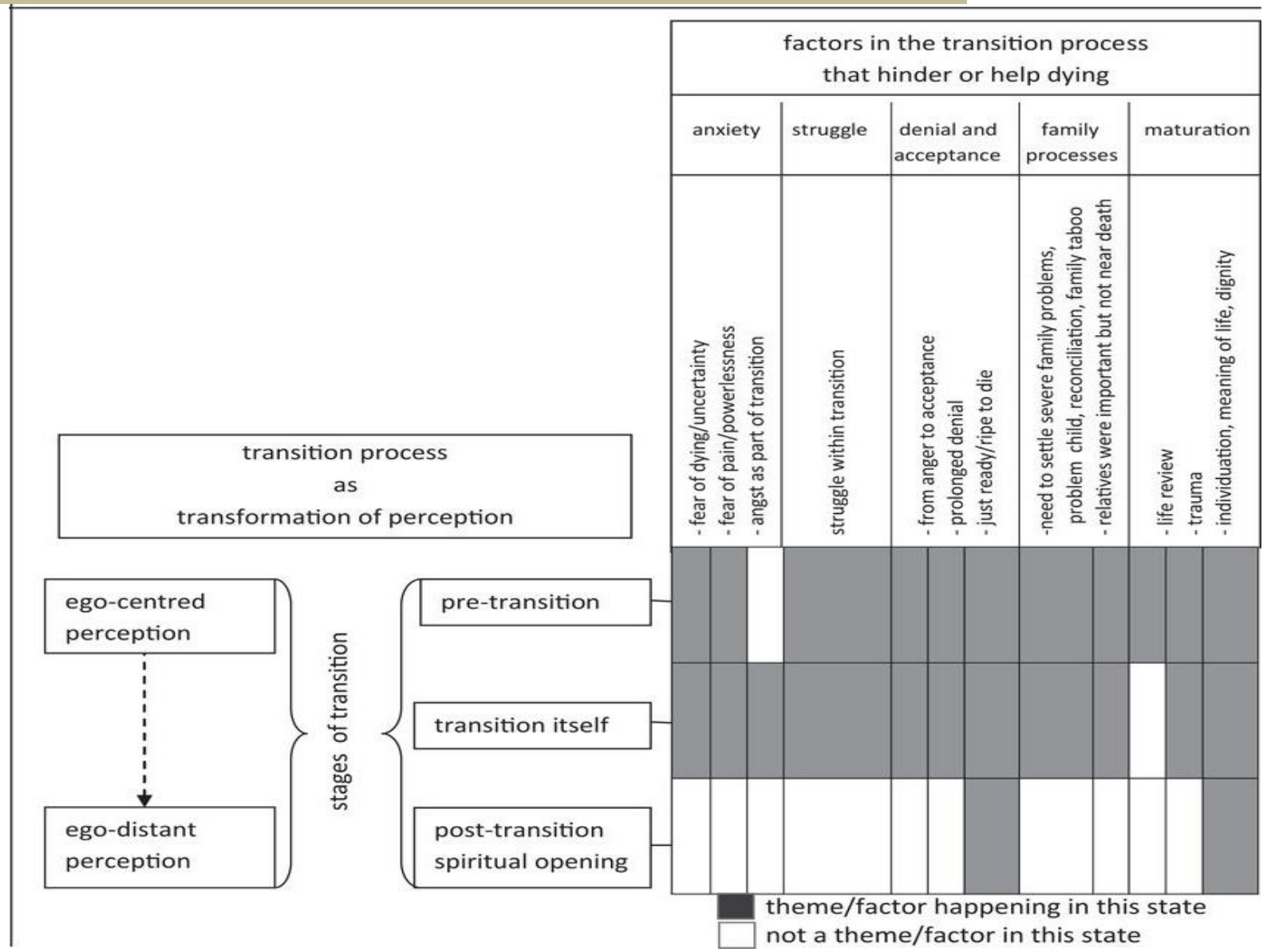
PREFERRED NAME _____

DATE ___/___/_____

GOAL : MEDICATION NEEDS REVIEWED BY DOCTORS & ADJUSTMENTS MADE AS NECCESARY		
DAY		
NIGHT		
GOAL : HOLISTIC ASSESSMENT COMPLETED & NEEDS OF PATIENT AND PEOPLE MOST IMPORTANT TO THEM MET (EMOTIONAL, SPIRITUAL, CULTURAL, PRACTICAL)		
DAY		
NIGHT		
GOAL : MOUTH CARE DELIVERED AND ORAL HYGIENE MAINTAINED		
DAY		
NIGHT		
GOAL : ORAL HYDRATION IS MAINTAINED & ASSISTANCE PROVIDED TO DRINK AS ABLE/DESIRED		
DAY	Oral hydration estimate: None☐, <500ml☐, 500-1000ml☐, 1000-1500ml☐ >1500ml ☐	
NIGHT	Oral hydration estimate: None☐, <500ml☐, 500-1000ml☐, 1000-1500ml☐ >1500ml ☐	
GOAL : ORAL NUTRITION MAINTAINED & ASSISTANCE PROVIDED TO EAT AS ABLE/DESIRED		
DAY		
NIGHT		
GOAL: MICTURITION/CATHETERS & BOWEL/STOMA CARE: COMFORT & DIGNITY MAINTAINED. APPROPRIATE CATHETER CARE AND URINARY SYMPTOMS MAINTAINED		
DAY		
NIGHT		
GOAL: HYGIENE, SKIN INTEGRITY AND COMPLICATIONS OF BEING IN BED: COMFORT AND DIGNITY MAINTAINED, APPROPRIATE PRESSURE AREA CARE ADDRESSED		
DAY		
NIGHT		

IF GOALS NOT MET DURING SHIFT PLEASE DOCUMENT WHY AND WHAT ACTION HAS BEEN TAKEN
CONTINUE DOCUMENTATION OVERLEAF IF REQUIRED

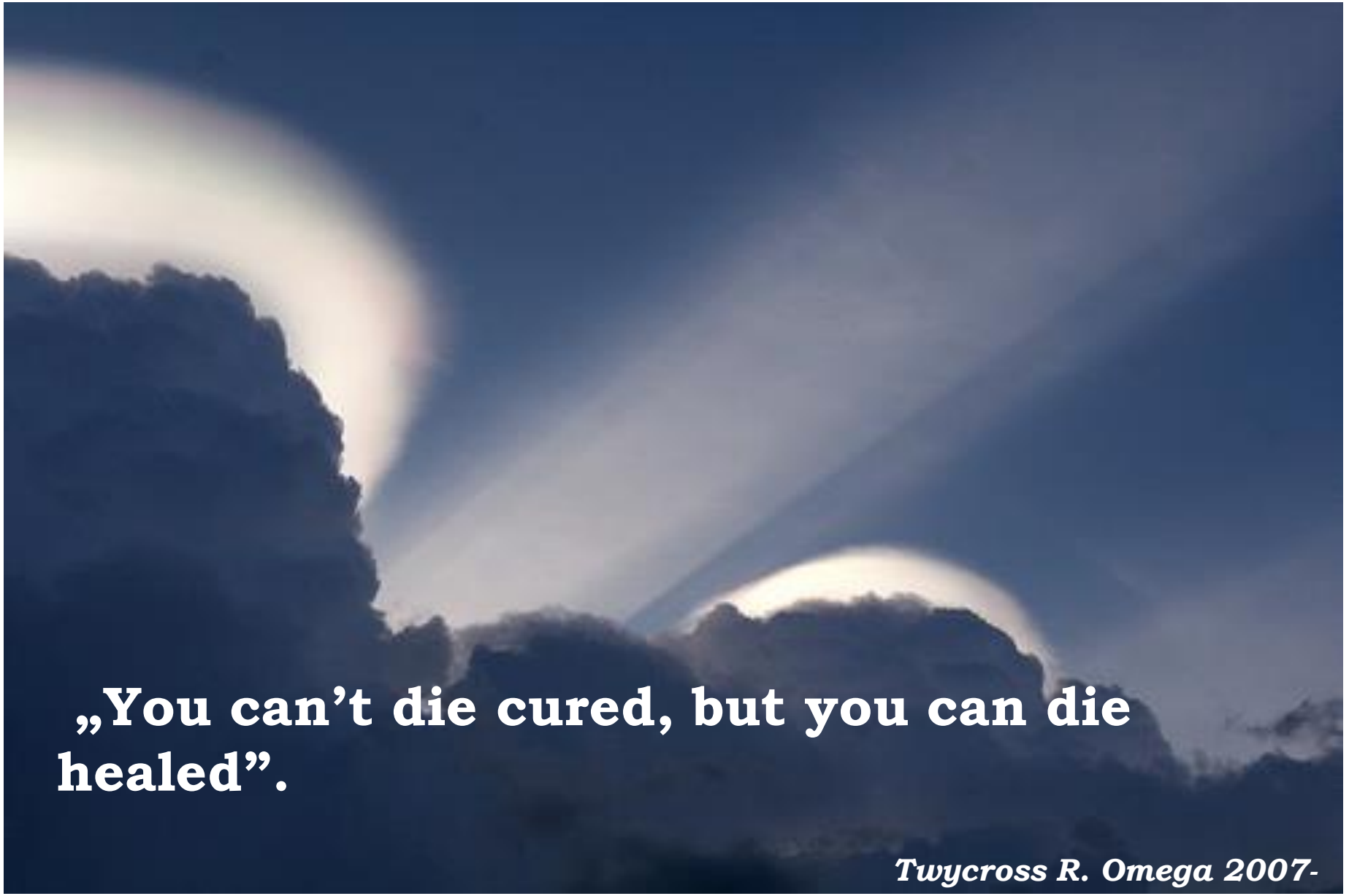
N = 80 (pilot study) + 600 (follow-up study)



Dying as a spiritual process

Monika Renz. Dying a transition. Columbia University Press, New York 2015

Renz M, Mao MS, Bueche D, Cerny T, Strasser F. Dying is a transition. Am J Hosp Palliat Care 2013; 30(3):283-90.



When doors of heaven open by Martien van Asseldonk