Building the capacity for palliative care in residential homes for the elderly in Hong Kong

Samantha Mei-che PANG
RN, PhD, Professor
School of Nursing, The Hong Kong Polytechnic University

Why palliative care approach?

- What are the values to the elderly residents?
- Will the resident and family care experiences be improved?
- Will the residents’ dying experiences be improved?
- Will the serving staff’s work experiences be improved?

- **Elderly population in Hong Kong**

	2001	2006	2011
>=65	11.1%	12.4%	13.3%

(Census and Statistics Department HKSAR, 2012)

The proportion of the population aged 65 and over is projected to rise markedly from 13% in 2011 to 30% in 2041.

(Census and Statistics Department HKSAR, 2012)

- **Health status of Hong Kong residents**

Age Group	Persons who had chronic health conditions
<25	9.2%
25-34	5.7%
35-44	9.4%
45-54	18.2%
55-64	22.5%
>=65	**34.9%**

(Census and Statistics Department HKSAR, 2013)

- **Hospital admission**

Age Group	In-patients admitted into hospitals over 12 months	Number of admissions over 12 months	
		Once	*Twice and more*
<5	7.0%	7.1%	6.6%
5-14	3.9%	4.4%	2.0%
15-24	4.2%	4.9%	2.2%
25-34	10.8%	12.0%	7.0%
35-44	12.7%	14.5%	7.2%
45-54	14.5%	15.5%	11.6%
55-64	16.1%	14.3%	21.9%
>=65	**30.8%**	**27.3%**	**41.5%**

(Census and Statistics Department HKSAR, 2013)

- ‘Hospitals, community care services and care homes should provide a seamless end-of-life care service to enable individuals and their families to exercise choices in their end-of-life care, including dying at home or in their care home. Hospital admissions should be avoided where possible, if that is not the wish of the individual.’

Delivering Dignity: Securing dignity in care for older people in hospitals and care homes, Commission on Dignity in Care, June 2012

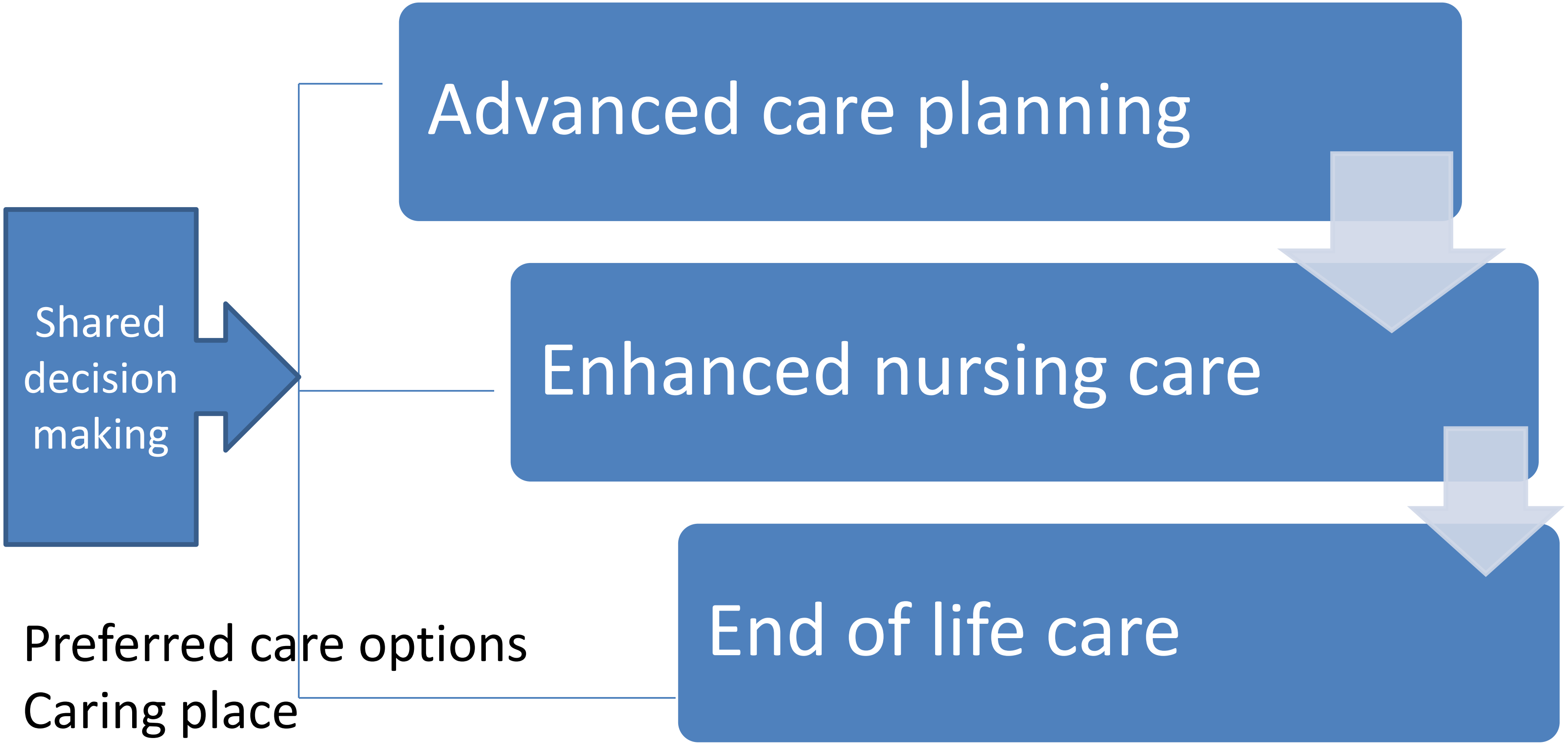
More care, less pathway: A review of the Liverpool Care Pathway (July 2013)

Issues raised:

- Shared decision making
- Communication and coordination
- Quality patient care experience

Recommendation: an individualized end of life care plan, and condition-specific good practice guidance.

Palliative care in residential homes for the elderly (HKAG &SAHK, 2010-13)



Shared decision making

Advanced care planning

Enhanced nursing care

End of life care

Preferred care options

Caring place

Focus group interviews, May-June 2013

- Examine the experience of co-residents who have involved in the palliative care program
- Examine the experience and opinions of care providers about the implementation of the palliative care program
- Six focus groups, N=32

Co-residents’ attitude towards end of life care

- This is a reality that each month we had a few co-residents passed away
- I have no control of what would happen when I die, I want to live my days in happiness now
- When the days come, I wish not to have too much suffering, and to have peace and comfort
- I have to fully trust the elderly home’s staff
- Preference to stay in the PC room depends on whether there is someone to be with me
- I do not want to be left alone
- Having health professionals around make me feel more confident

Co-residents' healthcare experiences

- Improvement of healthcare service as compared to the old days
- I knew that I am in good hands
- Being approached with caring attitude
- Being attended promptly in times of urgency
- Being treated with respect
- Clear explanation with reassurance
- Demonstrating professional efficiency

- I could scarcely see a nurse, most of the time is only supporting staff around
- Being confronted with offensive words
- Being treated with indignities
- Procrastinating action in times of urgency
- Being kept in the dark or being misinformed
- Just getting the job done

Care providers’ challenges

- Anticipating is the watchword: anticipating what will happen and what to tell residents and their relatives.
- Value differences and value change over time
- Prognostication
- Symptom control measures
- Provision of hydration and nutrition
- Certainties of the dying process
- Lack of control over the implementation of the end-of-life care plan

Right people at the right time

- Caring for the dying, high levels of technical competence, compassion and communication are required.
- Professional standards of care are required to look after people who may have co-morbidities, be in pain and frightened, and their distressed and anxious families.
- Constant pressures on staff and that some find the workload unmanageable
- 24 hours available and accessible

Capacity for palliative care

Staffing

- Improved workforce planning to ensure sufficient staff are trained with the right skills
- Staff retention and job satisfaction in residential care homes

Facilities

- Palliative care facilities in place
- Adaptability of care resources in alignment with residents' care demands, such as de-stigmatization of PC room

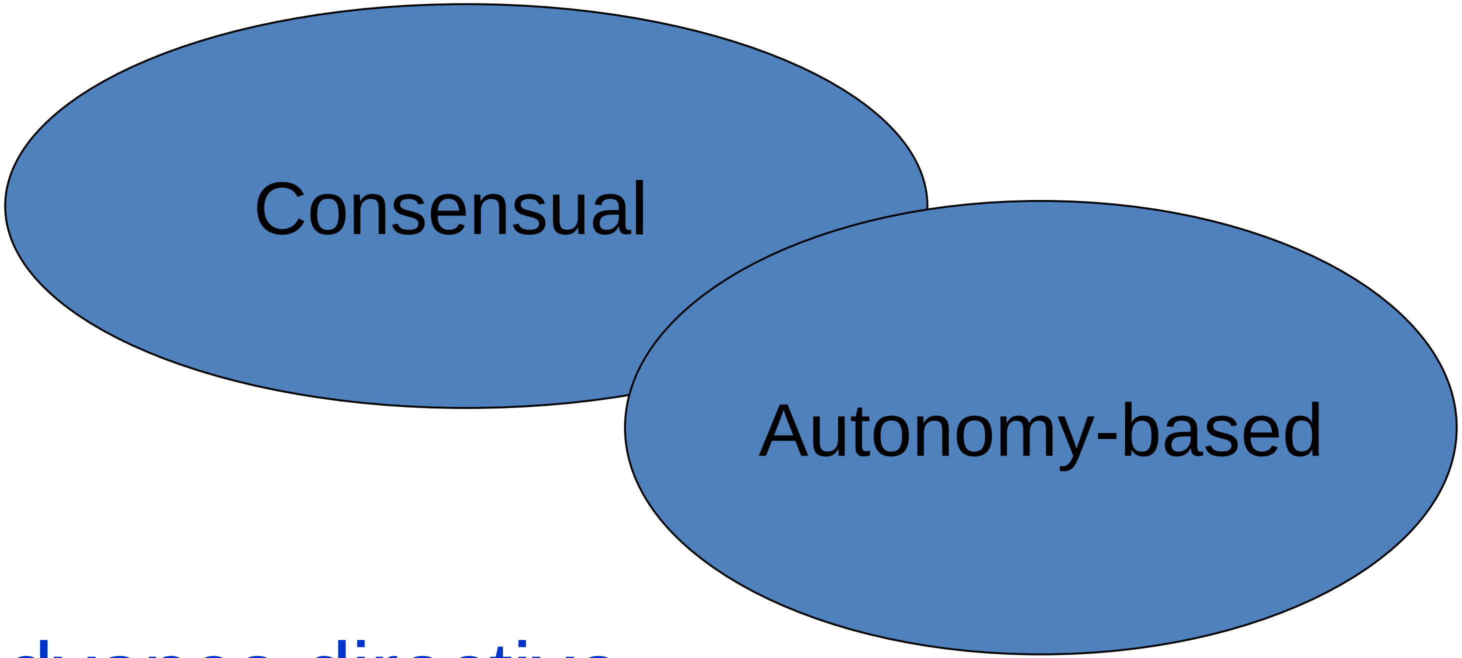
System

- Properly constituted multidisciplinary specialist services available for support around the clock as a hub of expertise, support and training
- Cross-systems communication and coordination

An explicit hospice philosophy based on the articulated core values of compassion, comfort, and dignity.

Two patterns of decision-making

Advance proxy care planning



Consensual

Autonomy-based

Advance directive

Advance decision-making with respect paid to the individual’s wishes

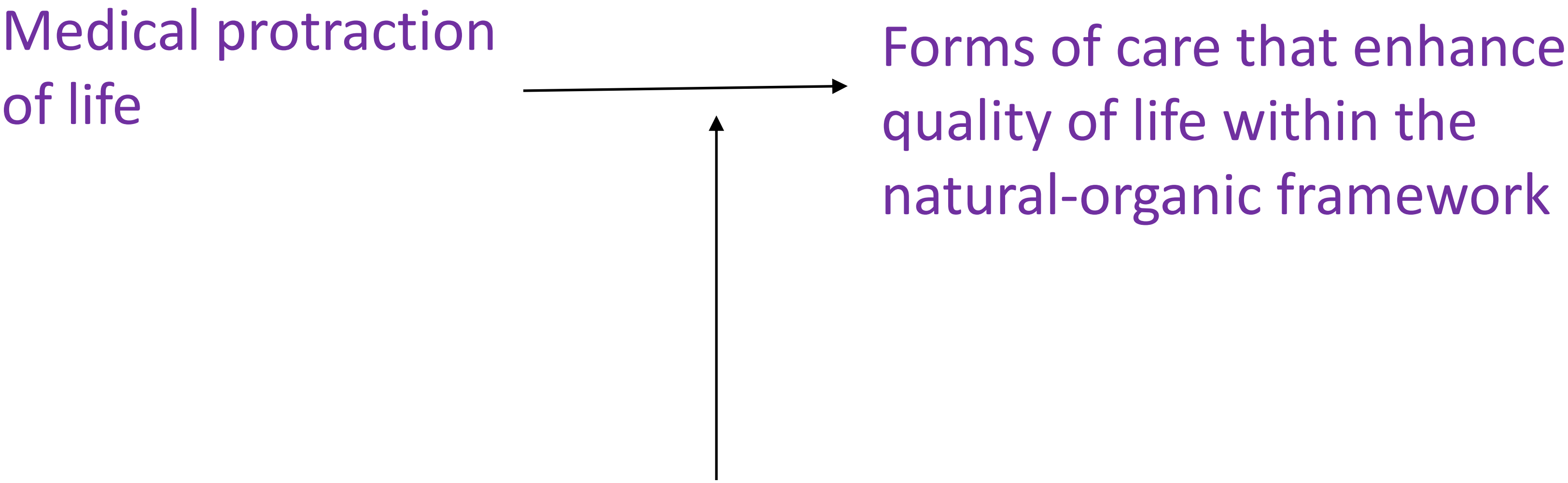
- An acknowledgment of making an advance directive as a part of one’s responsibility in life.
  - “It’s something that we should do…. You should decide things like that when you know what you’re doing, not wait until it is too late.”
- The other reason stemmed from their traumatic experiences witnessing the prolonged suffering endured by their dying parents whose lives had been sustained with invasive medical technological devices. They did not want this to happen to them.

Advance proxy care planning focusing on individual's comfort

We just don't believe in it."

- The insertion of a tube would definitely cause discomfort to the individual, but insufficient intake and the consequent weight loss might not.
- They saw the declining ability to swallow as a natural progression of the disease process instead of a medical condition to be treated.
- They were convinced that the ways in which the healthcare team offered better alternatives in dealing with the feeding problems of their loved ones.

Paradigm shift of goals of care

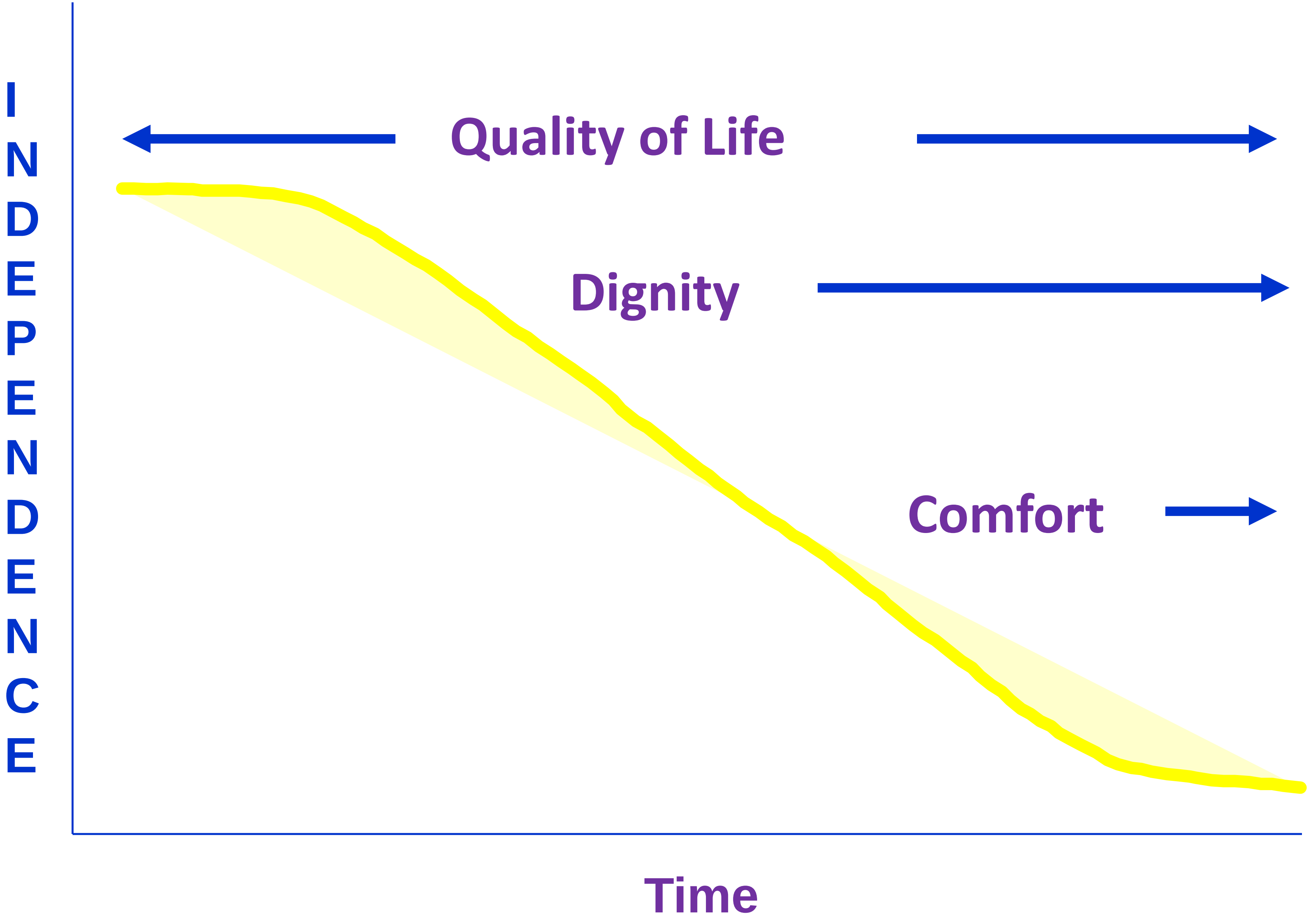


Medical protraction of life

Forms of care that enhance quality of life within the natural-organic framework

- Goal of care: quality of life improvement
- Shared decision making
- Relational approach of “trying to do everything for the individual”

Goals of Care



Quality of Life

Dignity

Comfort

INDEPENDENCE

Time

Concern of Comfort Care

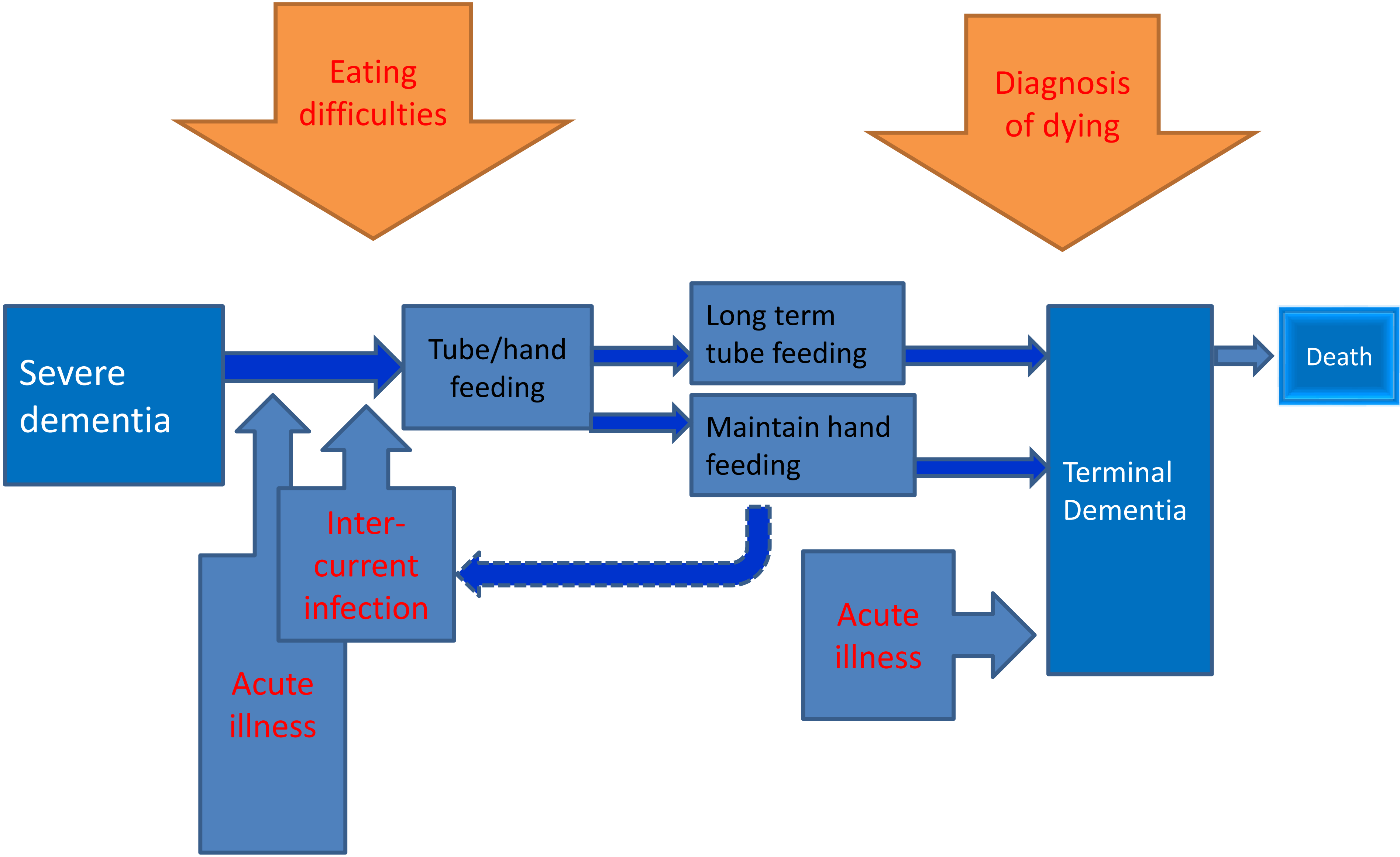
- Discomfort Scale for patients with Dementia of the Alzheimer Type

- PAINAD

PAINAD Scale

	0	1	2	Score
Breathing	Normal Independent of vocalization	Occasional labored breathing Short period of hyperventilation	Noisy labored breathing Long period of hyperventilation Cheyne-stokes respirations	
Negative Vocalization	None	Occasional moan or groan Low level speech with a negative or disapproving quality	Repeated troubled calling out Loud moaning or groaning Crying	
Facial expression	Smiling, or Inexpressive	Sad, Frightened, Frown	Facial grimacing	
Body Language	Relaxed	Tense, Distressed pacing, Fidgeting	Rigid, Fists clenched, Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
				TOTAL

Decision making along the end of life trajectory



- Organizational culture as main difference between high (41.8%) and low (10.7%) tube feeding rates in patients with advanced dementia
  - Physical environment
  - Care processes for feeding
  - Decision making process
  - Values

Lopez et al. (2010) The influence of nursing home culture on the use of feeding tubes. Archives of Internal Medicine 170(1),83-88

Aspect	High tube feeding rate	Low tube feeding rate
Physical environment	Institutional like environment	Homelike environment centered on food as an important component of daily life
Care processes for feeding	Poorly staffed mealtimes	Mealtimes staffed with knowledgeable nursing assistants who valued hand feeding
Decision making process	No explicit advance care planning in place	Advance care planning that included family and palliative care options

Aspect	High tube feeding rate	Low tube feeding rate
Values	•Staff attitudes favoring feeding tubes to avoid aspiration and to meet perceived regulatory compliance •Health professionals found difficulty to undo family beliefs that feeding tubes were in residents’ best interest	•Health professionals’ attitude reflected a preference for hand feeding over tube feeding •If family are “willing to take the risk”, staff were willing to hand feed residents, despite the possibility of aspiration •Not apprehensive about meeting regulations concerning weight loss by multiple strategies to maintain weight, family involvement and meticulous documentation

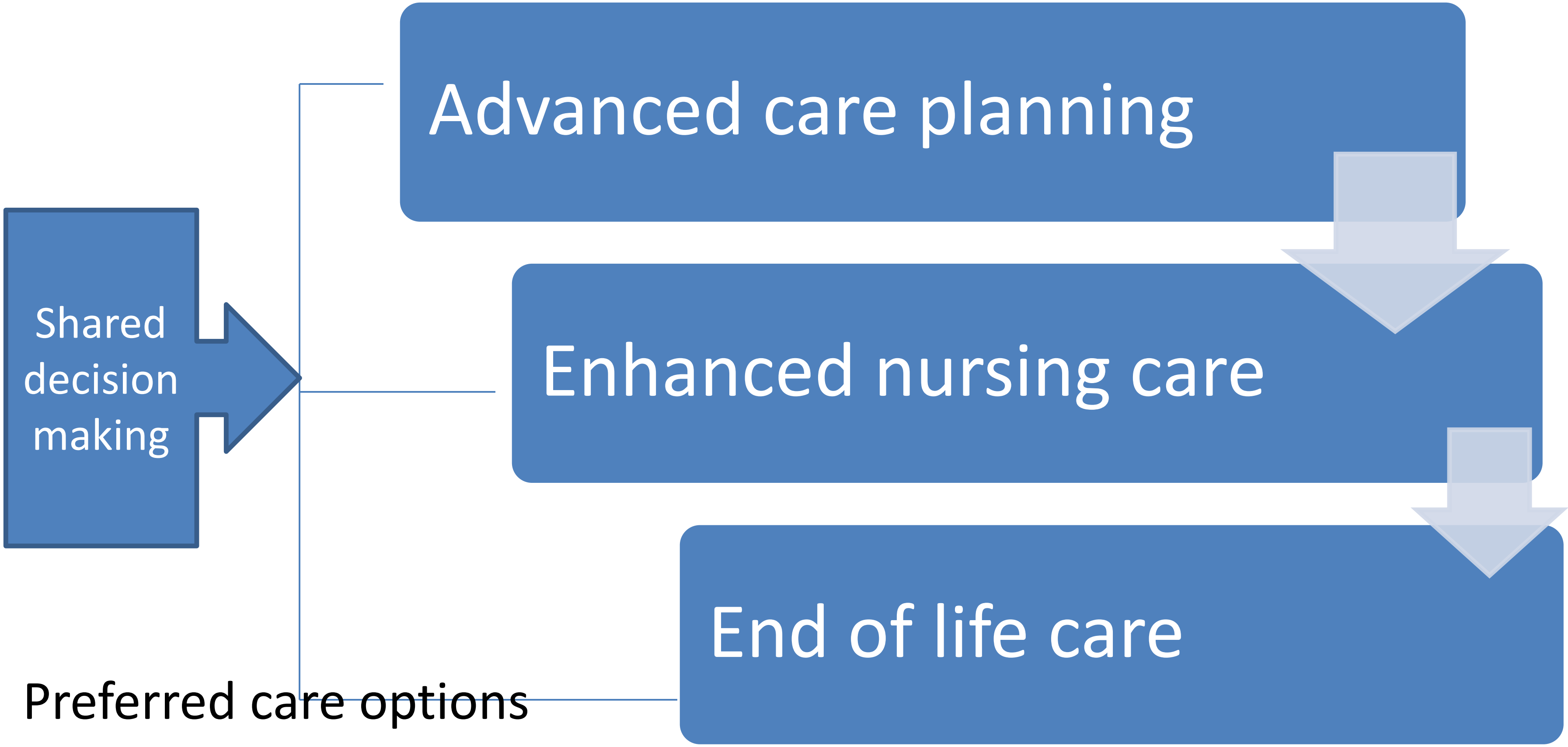
Relational approach of "trying to do everything for the patient"

- In the last days, the patients might virtually stopped eating, but the care providers did not "stop taking care of the patients'."

- To hold on to these beliefs as the families accompanied their loved one in the dying process was no easy task.

- Many consulted their adult children's opinions, have had them participated in the regular family meetings, and wanted to be assured of their support.

Capacity building for palliative care



Shared decision making

Advanced care planning

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End of life care

Preferred care options
Caring place
Improved care experiences for residents, families and staff

Thank you