



**A BUDDHIST NUN WHO
WANTS NO PROLONGATION
OF SUFFERING**
ADVANCE CARE PLANNING

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- 涅槃(煩惱寂滅, nirvana, cessation of suffering)
- 娑婆世界 vs. 西方淨土
- 往生極樂



CASE 1

- Md Sik, 74/F Buddhist nun
- Living in a Temple in Fu jian
- ADLI
- Past history of Ca cervix with operation done >10 years ago.

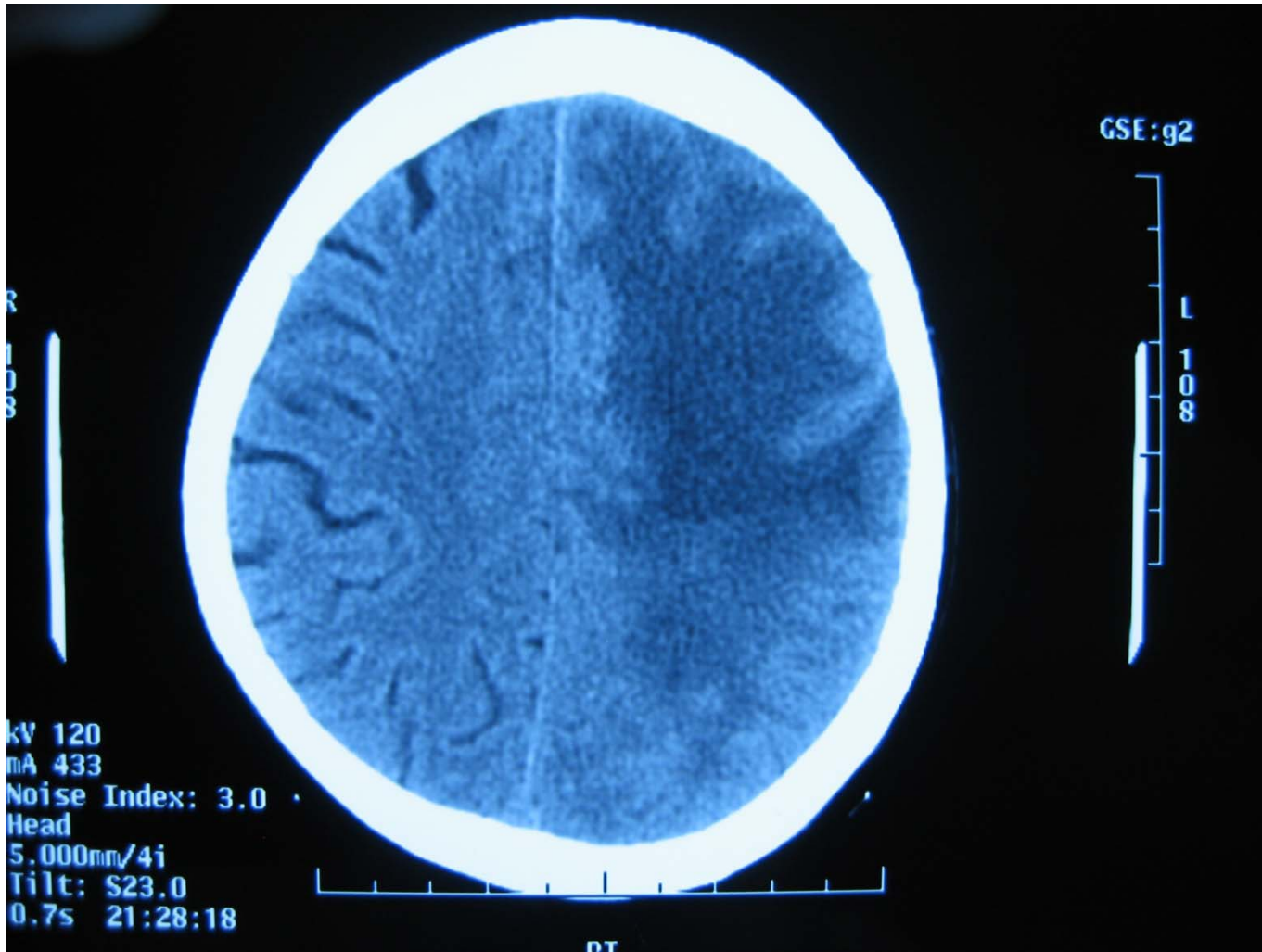
History of Present illness

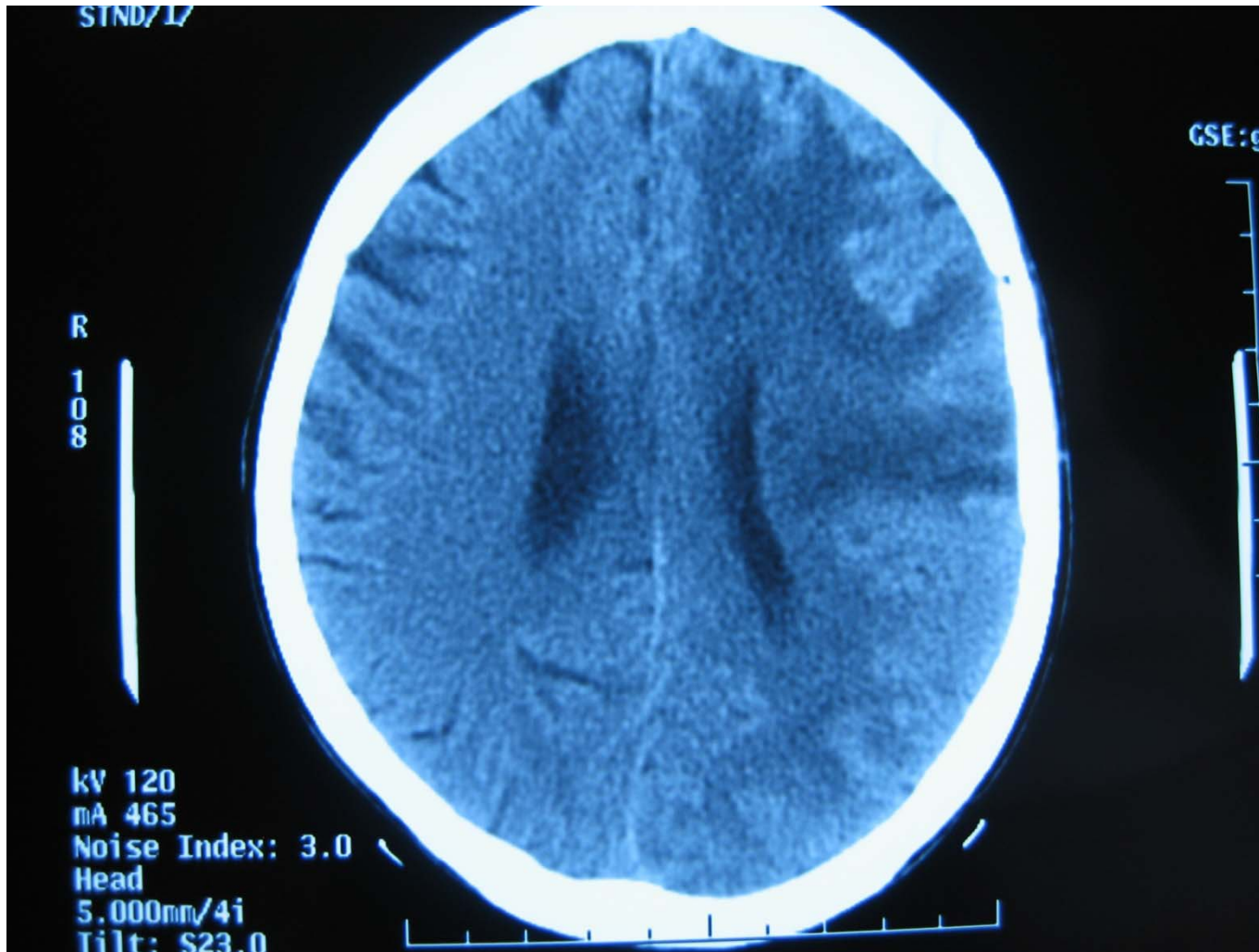
Sudden onset right hemiplegia and loss of speech
10 days before the present admission (12 May
2010)

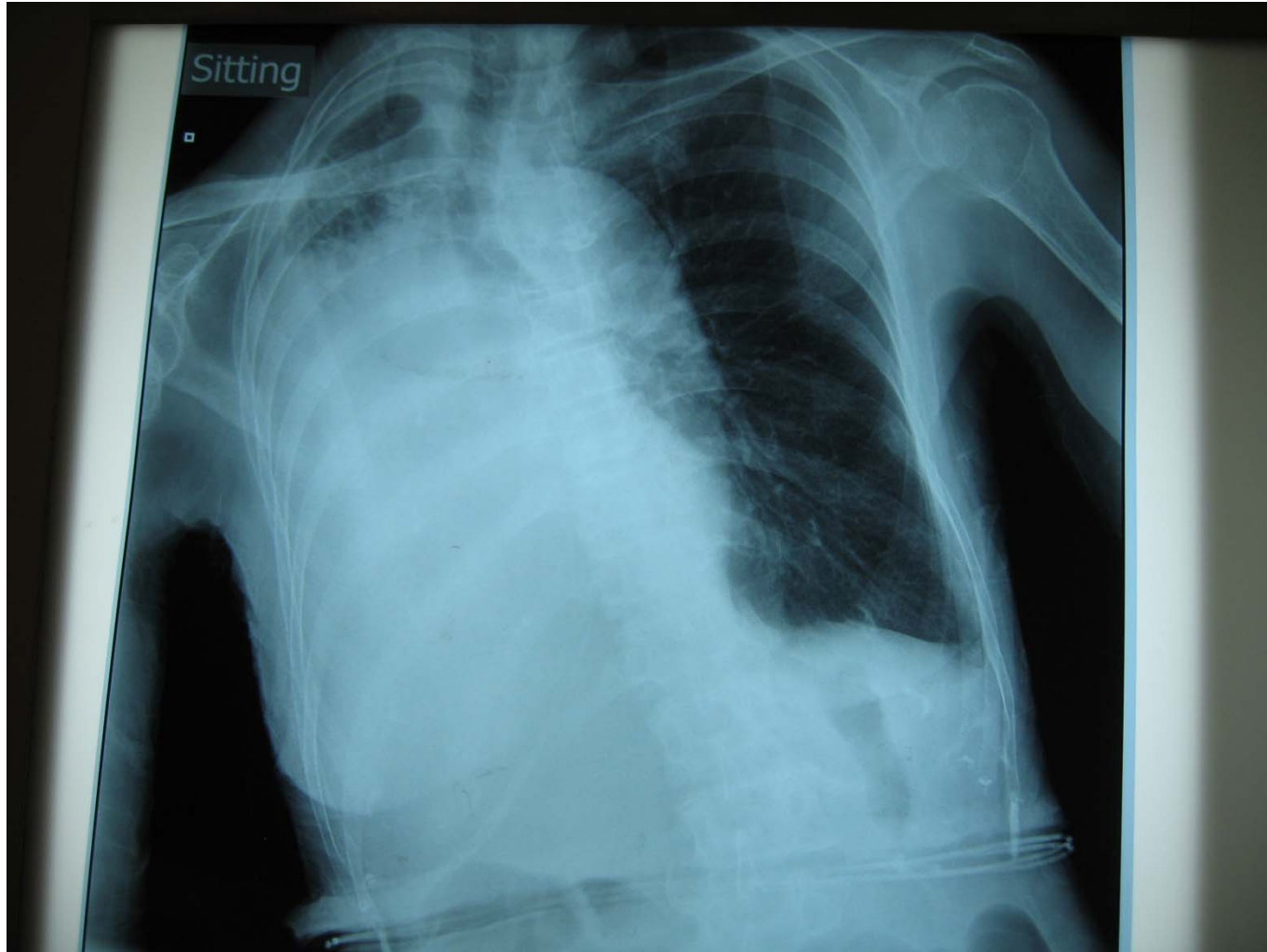


- She was brought back to Hong Kong by her daughter and attended A&E of NDH.
- CT brain was done because of suspected stroke and showed gross left cerebral edema.
CXR also showed opacified right lung
- Her daughter refused admission to NDH and brought her to KWH for seeking of second opinion
- CT brain and CXR was repeated and showed similar findings.









- On admission, she was aphasic with right hemi-neglect. There was spontaneous left sided movement but no right sided movement.
- Her daughter was seen by the on call medical officer and a provisional diagnosis of metastatic brain tumor was told.
- She totally accepted the diagnosis but all that she only wanted to know was whether there would be treatment that could make her mother walk and speak again



- It was explained that her mother's condition was incurable but may improve with treatment
- She was informed of a possible need of Ryles'tube insertion for temporary nutritional support and medications before patient's swallowing ability returns (she failed swallowing test)
- She had a strong reaction because she did not want her mother to suffer.
- She claimed that her mother had mentioned recently that she would not like to have insertion of tube for feeding nor resuscitation should she develop critical illness.
- Besides, to comply to the wish of her mother, she requested discharge of her mother to bring her back to the temple where she would spend the rest of her life



- Md Sik was given iv dexamethasone and her general condition improved the next day.
- Basic communication was possible by yes/no (by gripping or loosening of grip).
- She responded that she liked treatment that could make her feel better and accepted temporary tube feeding if considered helpful by doctor.
- Her swallowing ability also improved with iv dexamethasone. Oral feeding was allowed by speech therapist, with modification of diet



- Md Sik's daughter had arranged residency for her mother in a private convalescent hospital (The Hong Kong Anti-Cancer Society Jockey Club Rehabilitation centre) and she was discharged on 17 May 2010



DIFFICULT SITUATION (COULD I DO MORE)

- Can I just follow patient's daughter interpretation of her mother's expressed wish?
- Is the expressed wish before admission enough to guide the management of this patient?
- Even if there is an advance directive, is it adequate?
- Does she have an idea of what had happened to her and would she change her mind if she knows more?
- Could I let this patient be discharged back to China if her daughter insists?
- If not, who should decide?



Problems with AD/living wills

- Cannot always enhance/respect patients' autonomy
 - Patients may not be able to understand future hypothetical scenarios and to reject certain treatments in those situations
 - Example: imagine a 93 year old patient with congestive heart failure with episodic exacerbation , generalised crippling osteoarthritis and carcinoma of prostate with metastasis



CASE 2

- 86/F Md Ho
- OAHR
- Single, no relative
- Ex-employer
- Hx of DM, with PVD and toes gangrene (for conservative treatment), renal impairment, COAD and advanced dementia (can barely communicate)
- Dependent ADL, oral feeding
- Admitted for decreased general condition for 1 day with SOB.



- ECG showed complete heart block with heart rate of ~40 bpm
- Temp 35.1 C
- SBP~90 mmHg.
- Na 137 K 8.5 urea 47.6 Cr 567 (Cr was 170 one month before)
- WCC 14.7 Hb 6.2 g/dl INR 1.73 APTT 34.9
- CSU showed WCC>100/ul (turned out growing ESBL strain of E Coli after her death)






- Problem lists

- acute renal failure
- Hyperkalemia causing complete heart block
- Severe metabolic acidosis with Kussmaul breathing
- shock
- Anemia
- Sepsis

- She was treated with

- Standard treatment for Hyperkalemia (DI drip, Calcium injection, resonium)
 - Blood transfusion
 - Intravenous Antibiotic
 - Inotrope
 - NaHCO₃ infusion
 - 100% oxygen
- 

- She remained in poor shape and died 2 days later.
- No resuscitation was carried out.



SHOULD I DO LESS?

- Should or Could I just let natural death occur?
- Should I just give her oxygen?



- ACP\advanced
directive\ad_consultation_paper_en.pdf



OUTLINE

- What is Advanced Care Planning (ACP)?
- ?specific target groups
- What is the difference between ACP and AD (advanced directive)?
- Benefits of ACP?
- How to carry out ACP? Overall view of ACP in different countries?
- Barriers to ACP
- How to enhance ACP
- ?Local data (none)



ACP: CONCISE EVIDENCE-BASED GUIDELINE ROYAL COLLEGE OF PHYSICIAN 2009

- ACP is defined as
 - a process of communication
 - Between an individual, their health care provider and those close to them
 - About goals and preference of future care , esp. to the end of life
- **Usually** associated with end of life care
- **Usually** assumed to result in a documentary record or 'advance statement



- Appropriate for all adults and for the subset with life-limiting illness
- Focuses on conversation and addresses surrogate decision-making and end-of-life preferences
- There is a shift of focus of ACP from eliciting refusal of treatment from a minority of patients to identifying the preferences for care of most patients



TARGET GROUPS OF ACP

- In US, for All adults
 - Legislation requires that all individuals admitted to a care home are offered ACP
- In Australia, for All adults, with emphasis on elderly, particularly nursing home residents
- Canada
 - For all capable adults
 - For those who are healthy, those living with a chronic condition or disease, or those approaching the end of life
- All patients with progressive life-threatening illness in UK
 - ACP is part of the NHS End of Life care Strategies



- [ACP\advanced directive\advance-planning.pdf](#)



UK national guidelines for ACP

- Patients with long term conditions or receiving end-of-life care
- Should be initiated in primary care or in the outpatient setting, before individuals become acutely unwell
- For individuals with progressive cognitive impairment
 - They should be offered ACP discussions early in their disease process



- Healthcare professionals should consider using clinical vignettes or examples as useful aids for ACP in individuals with moderate cognitive impairment
- Once a patient has lost capacity to make decisions about their future care, any care decisions of ADRT will need to be made in their best interests. If an LPA with relevant authority has been appointed they make the decision on behalf of the patient; in those circumstances detailed discussion with the attorney is essential



ACP IN CARE HOME

- entering a care home can be considered a pre-terminal event (1 year survival rate)
 - Nursing home 59%
 - Dual registered home 58%
 - Residential home 76%

Rothera 2002

- Care home residents often die in hospital when they may not have wanted to
- In a study, 100 residents (Sheffield 2007) died in hospital within 48 hours of admission



FACTORS ASSOCIATED WITH REDUCED LIFE EXPECTANCY IN CARE HOMES

- Malignancy
- Increasing age
- Male
- Malnutrition
- Limited physical function
- Respiratory illness
- Poor tissue viability



ACP IN UK (CARE HOMES)

- Use of ACP in GSF (Gold standard framework)
 - On resident on admission to care home
 - & when there is Life changing event, e.g. death of spouse or close friends or relative
 - Making or changing a will
 - Following a new diagnosis of life limiting condition
 - Multiple hospital admissions



- GSF template
 - Thinking ahead
 - Open questions
 - What matters to you
 - What you wish to happen
 - And what not to happen
- Proxy-who else involved +who to call in a crisis
- Preferred place of care and death, options
- Other request e.g. special instructions



ACPS IN CARE HOMES

- Improved communication with residents and families early on
- Improved planning of care
- Reduced crises
- Help formalize discussion using a tool
- DNAR difficult-prefer 'allow natural death'
- Some found that they were difficult discussions
- All like having them-useful and clear



IN AUSTRALIA

- The Respecting Patient Choices (RPC) model of advance care planning was implemented in residential Aged Care Facilities (RACFs) in Melbourne in 2004-05 and has subsequently been implemented in over 70 other RACFs in Victoria and around Australia.
- The initial implementation in 17 RACFs involved over 1100 aged care residents and has been extensively evaluated (Silvester Feb. 2006). The median age of the residents was 86 and only one-third of the residents still retained capacity to make legal decisions



- More than half of the residents or their families (as substitute decision-makers) approached by the staff completed written Advance Care Plans.
- Nearly two-thirds of these were completed by family members on behalf of noncompetent residents, many of whom had advanced dementia.



- The vast majority of written requests were for no life-prolonging measures, but instead, to receive palliative care near the end of their lives. Less than 20% wanted to go to hospital.
- The outcome of this model of discussion and documentation was that, for all the residents who died during 2004-05 who had an Advance Care Plan, 85% received end-of-life care in their facility
- Whereas, for those residents without Advance Care Plans, 67% died in hospital while being cared for by staff who did not know them.



RESPECT PATIENT CHOICES MODEL

- [ACP\advanced directive\RPC-Information-Booklet.pdf](#)
- [ACP\advanced directive\RPC-ACP-Guide.pdf](#)
- ‘people and family centered’



Outcome of ACP

ACP may lead to

1. An advance statement (a statement of wishes and preferences)
2. An advanced decision to refuse treatment (a specific refusal of treatment(s) in a predefined future situation)
3. The appointment of a personal welfare lasting power of attorney



ADVANCE DIRECTIVES

- Instructions made in advance when a person is competent
- Become applicable when the person has lost capacity for making medical treatment decisions (e.g. comatose)



- The scenarios in which an AD will be activated -
 - 1. Terminal illness
 - 2. Irreversible coma
 - 3. Persistent vegetative state

- terminally ill:
- advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months.



- ‘life sustaining treatment’:
 - CPR,
 - artificial ventilation,
 - blood products,
 - pacemakers,
 - vasopressors, specialized
- dialysis,
- antibiotics (when given for a life threatening infection)
- artificial nutrition and
- hydration



- Traditional understanding of the benefits of advance care planning
 - Respect for autonomy
 - Preparation for possible future incapacity
 - Completion of formal advance directives



BENEFITS OF ACP

- From patient's perspective
 - Subjective, psychosocial
- From relative's aspect
 - Relief of the burden to make a life and death decision in short notice
- From health care provider's perspective
 - economical



FROM PATIENTS' PERSPECTIVE

SINGER ET AL ARCH INT MED 158(8)879-84, 1998

- To prepare for death
- Underlying goals
 - Exercise of control
 - Relieve burdens placed on loved ones
- Social process
- An AD form was often regarded as unnecessary
- ACP does not occur solely with the context of the Physician-patient relationship but also within the context within the relationship with close loved ones



THE IMPACT OF ADVANCE CARE PLANNING ON END OF LIFE CARE
IN ELDERLY PATIENTS : RANDOMIZED CONTROLLED TRIAL
KAREN ET AL BMJ 2010;340:C1345

- Prospective randomized controlled trial
- single centre study in a university hospital in Melbourne, Australia
- Participants: 309 legally competent medical inpatients aged 80 or more and followed for six months or until death
- randomized to receive usual care or usual care plus facilitated advance care planning



○ Results

- 154 of the 309 patients were randomized to ACP
 - 125 received ACP
 - 108 expressed wished or appointed a surrogate or both
 - Of the 56 patients who died by six months, end of life wishes were much more likely to be known and followed in the intervention group (86%)
- With ACP, family members of patients who died had significantly less stress, anxiety and depression than those of the control patients
 - Patients and family satisfaction was higher in the intervention group



ADVANCE CARE PLANNING AND HOSPITAL IN THE NURSING HOME

CAPLAIN ET AL AGE AND AGEING, 2006;35: 581-585

- After educating residents, their families, staff and GP about outcomes of dementia, ACP and hospital in the home, emergency calls to the ambulance services from nursing home with ACP decreased
- The risk of a resident with ACP being in a hospital bed for a day fell by a quarter than before the implementation of ACP
- With the implementation of ACP, there was no significant change in mortality while in the control Nursing home (with no ACP), the mortality rose in the third year of study



- 2 points stressed by the investigators
 1. Education about dementia and ACP in Nursing Home leads residents to receive treatment for acute illness in the nursing home rather than in hospital
 2. Decreasing nursing home residents' admissions to hospital decreased their mortality



Cost reductions

- A randomized controlled trial involving 1292 residents in six Canadian nursing homes found that facilities promoting living wills had fewer hospitalizations per resident and lower health care costs per resident (Can \$3490 vs Can 5239)
- A retrospective study of 336 patients who died in a US university hospital found that patients with living wills spent less than 3 days in intensive care unit while those with none spent over 5 days and their hospital charges were 1.35 times higher (US 49900 vs US 31200)



- Any cost reduction associated with ACP is probably related to avoiding 'terminal hospitalization' or because people with ADRT are less likely to receive life sustaining therapy when hospitalized or ICU care
- Studies show that care in the last week of life of patients with advanced cancer who had had end-of-life discussions with their physicians were 35 per cent less costly



- Cost could be saved by
 1. Decreased hospital admission
 2. Decreased invasive procedures or expensive treatment
 3. Decreased ICU admissions



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DO PATIENTS WANT TO DISCUSS THEIR PREFERENCES

- Yes and No
- For patients with chronic illnesses: yes
- For relatively healthy patients: no



- Hospitalized seriously ill: 63% wanted, 34% did
 - Elderly cardiovascular pt: 38% wanted, 9% did
 - Chronic heart failure pt: 70% wanted, 10% did
- Patients want their physician to bring up the subject
- Most patients want shared decision making
- Nolan et al J Pain Symptom Manage 2005;30:342-53



A CLINICAL FRAMEWORK FOR IMPROVING THE ADVANCE CARE PLANNING PROCESS: START WITH PATIENTS' SELF-IDENTIFIED BARRIERS

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY. 57(1): 31-9, 2009 JAN

- 143 subjects age 50 or older county general medicine clinic in San Francisco
- Measurement: 6 months after exposure to 2 advance directives, self-reported ACP engagement and barriers to each ACP step were measured with open- and closed ended questions using quantitative and qualitative analyses



- 40% did not contemplate ACP
- 46% did not discuss with family or friends
- 80% did not discuss with their doctor
- 90% did not document ACP wishes
- Six barriers themes emerged
 - Perceiving ACP as irrelevant (84%)
 - Personal barriers (53%)
 - Relationship concerns (46%)
 - Information needs (36%)
 - Health encounter time constraints(29%)
 - Problems with advance directives (29%)



WHEN TO DISCUSS?

- In health?
- Triggers?
- Most professionals and patients (>80%) agree that ACP should take place around the time of diagnosis of a life threatening illness
- Some patients with terminal disease or serious illness requiring hospitalization may not feel ready or able to so



REVIEW AND UPDATE

- Periodically
- Major life events e.g. death of spouse or close friend or relative
- Newly diagnosed chronic illness or life limiting illnesses
- Advancing chronic illness
- Significant shift in treatment focus e.g. chronic renal failure where options for treatment require review
- After complicated life-sustaining treatments
- Multiple hospital admissions



IMPLEMENTATION

- Barriers to implement ACP
 - Patient/individual factors (receptiveness and cognitive impairment)
 - Doctors factors (availability, unaware of need for ACP or difficult relationship with the patient)
 - Service factors (lack of funding, lack of time), doctors' beliefs about appropriateness and
 - System factors (lack of communication with providers, legislation)



- Study on how physicians communicate about advance directive
 - Conversations about AD lasted for 5.6 minutes
 - -patient's values were rarely explored in detail

Weiner et al Journal of Palliative Medicine 7(6): 817-29, 2004

Tulsky et al Ann Intern Med 1998;129: 441-449



○ How to enhance ACP?



USE OF VIDEO TO FACILITATE END-OF-LIFE DISCUSSIONS WITH PATIENTS WITH CANCER: A RANDOMIZED CONTROLLED TRIAL

JOURNAL OF CLINICAL ONCOLOGY.28(2):305-10, 2010 JAN 10

- use of a goals-of-care video to supplement a verbal description for end-of-life decision making for patients with malignant glioma concerning three levels of medical care
 - Life prolonging care (CPR, ventilation)
 - Basic care (hospitalization, no CPR)
 - Comfort care (symptom relief)



- Verbal narrative alone
 - Life-prolonging care: 25.9%
 - Basic care: 51.9%
 - Comfort care: 22.2%
- Video arm
 - Life-prolonging care: none
 - Basic care: 4.4%
- Comfort care: 91.3%
Uncertainty score:
 - Video arm 13.7%
 - Verbal group 11.5%
 - $P < 0.02$
- In the video arm. 82.6% reported being very comfortable watching the video



VIDEO DECISION SUPPORT TOOL FOR
ADVANCE CARE PLANNING IN DEMENTIA:
RANDOMIZED CONTROLLED TRIAL

ANGELO ET AL BMJ 2009;338:B2159

- evaluate the effect of a video decision support tool on the preferences for future medical care in older people if they develop advanced dementia
- randomized controlled trial
- 4 primary care clinics (two geriatric and two adult medicine) affiliated with three academic medical centers in Boston



- convenience sample of 200 older people ≥ 65 years of age living in the community with previously scheduled appointments at one of the clinic
- Mean age 75
- 58% women
- Intervention: verbal narrative alone or with a video decision support



Preferred goal of care

- Life prolonging care (CPR, mechanical ventilation)
- Limited care (admission to hospital, antibiotics, but no CPR)
- Comfort care (treatment only to relieve symptoms)
- With verbal narrative alone, 68(64%) chose comfort care, 20(19%) chose limited care, 15 (14%) chose life prolonging care and three (4%) were uncertain
- In the video group, 81(86%) chose comfort care, eight (9%) chose limited care, four (4%) chose prolonging care and one (1%) was uncertain.
- In the video arm. 82.6% reported being very comfortable watching the video



How about in Hong Kong

- ACP\advanced
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END
Thank you

