

Palliative Care and Chinese Culture

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Grand Rounds

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Plan

- Three Case Histories
- Comments on Pain and Symptom and QOL Assessment
- Palliative Care in Asia
- Spirituality
- Conclusion

Case History

- 71 yo Chinese man with L arm weakness
- CT showed brain metastases and hepatic and renal mass
- Request for biopsy refused, and family requested patient be told of pneumonia.
- Mistrust developed between family and staff and Ethics Committee called

J Palliative Med 2001;4:475-80

Case History Perspectives

Family

- Son-in-law chemist
- Discharge pt to fly back to China
- Dx would break

Spirit, early death

J Palliative Med 2001;4:475-80

Physicians

- MD should not lie
- Pt should know Dx

Case History

Ethics Committee

Sought the opinion of a Chinese doctor

Decision: MD should not lie

Ask patient whether he wishes to delegate
receiving medical information to the family

Patient agreed that family could receive medical
information and make decisions

Patient discharged without biopsy and returned to
China.

J Palliative Med 2001;2001;4:475

Discussion Points

- Truth Telling vs Non Disclosure
- Patient Viewpoints
- Communication styles
- Breaking Bad News
- Family Barriers to Truthfulness
- Models of Decision Making

Prevalence Non Disclosure

- Radiation Oncology Practice in Singapore
- Over a 12 month period, 369 new patients were seen, of whom 84% were Chinese, 66% non English speaking, and 47% palliative
- Requests for non disclosure occurred at time of intake. Patient would be asked what he knew and wished to participate. If he declined, then he was asked if he would like to delegate the decision to his family.
- Non disclosure of diagnosis occurred for 66 patients (17.6%). Non disclosure of prognosis occurred for 136 patients (36.8%)

Back, Psycho Oncol 2005;14:1052

Predictors of Non Disclosure - Diagnosis

<u>Variable</u>	<u>OR</u>	<u>95% CI</u>	<u>p</u>
Advanced age	7.7	3.5-16.8	<.001
Female	6.0	2.7-13.7	<.001
Non English Speaking			
	7.6	1.7-34.5	<.001
Palliative Treatment Aim			
	3.2	1.3-7.9	<.01

Generally patients who had never been treated for cancer

Back, Psycho Oncol 2005;14:1052

Do Patients Want to Know?

Telephone survey in Hong Kong

	<u>Strongly Prefers</u>	<u>Prefers</u>	<u>No Pref</u>	<u>Pref Not</u>
Dx	77%	18%	3%	2%
Px	79%	18%	1%	2%
Equal Partner	52%	32%	6%	10%
SDM	70%	20%	5%	5%

Fielding, Psycho Oncol 1996;5:321

Attitudes in Hong Kong

- Qualitative Study in a Nursing Home done by nursing home physician. Eight of 11 patients agree to participate, mean age 82, single
- Six of 8 did not want CPR, aware of it – avoid suffering, good age, not wanting to burden the young generation, unpleasant experience with NG tubes, accepting fate.
- No emotional trauma from discussing this.
- Preferred person is often the doctor to make decisions

Chinese Seniors in Toronto

- Qualitative study of 40 seniors greater than 65 yrs regarding EOL decisions
- Responded to a vignette of a comatose pt
- Rejected advance directives
- Hope
- Suffering and burden to family and medical staff
- Future beyond human control
- Emotional harmony
- Life cycle
- Respect for doctors
- Would consider advance directives if with serious illness

Bowman, Soc Sci Med 2001;53:455-64

Communication Styles

High and Low Context

High Context

Group Orientation
Implicit messages
Indirect, emphasis on
nonverbal
Low literalness
Harmony and cooperation

Low self disclosure
Silence respected

Low Context

Individual orientation
Explicit and precise
Direct, verbal
communication,
High literalness
Confrontation and
competition

High self-disclosure
Silence is anxiety
producing, non
communicative

High Context vs Low Context Countries

- Saudi Arabia
- Mexico
- Japan
- China
- Nigeria
- South Korea
- Kenya
- France
- Spain
- India
- Germany
- Switzerland
- Denmark
- United States
- United Kingdom
- Canada
- Australia

Indirect Communication

Patient returns to see doctor after having a barium swallow for abdominal pain.

Patient – Was there anything serious?

Doctor – No

Patient – Is an operation needed?

Doctor – No

Patient – Any special diet necessary?

Doctor – No

Message – the patient has gastric cancer

Kurosawa, Ikiru

Perspective

- Discussion of death is the same as wishing death, and may precipitate death.
- Cancer is a stigmatizing illness
- Patients should be spared from worry or distress
- Culturally acceptable medical decision by family

Tong J Palliative Care 1994;10

Breaking Bad News - Diagnosis

Chinese doctors have traditionally been told to be honest with patients; veracity is a key Confucian value.

Philosophically, death is not feared in Confucian, Taoist or Buddhist traditions.

Suggestions

- 1) Care in using words such as death, cancer, fatal illness
- 2) Involve family early in communication and decision making
- 3) Accept delegation of decision making to family
- 4) Convince family members about approaching patients to give bad news.

Tse CY et al. J Palliative Med 2003;17:339-43.

Family Barriers to Truthfulness

Survey of 252 palliative care workers

- Families who do not know how to tell the patient the truth
- Not necessary to tell older patients the truth
- Patients can be happier without knowing the truth
- Family unable to manage the patient's emotional reactions
- Medical failure and imminent death
- Patients will be sad and commit suicide

Hu, Cancer Nursing 2002;25:486-92

Strategies to Deal with Barriers

- discuss the sickness gently with patients and determine what the patients know
- identify what patients and families know and find the appropriate time and person to give more information
- encourage the family to accept the patient's prognosis
- tell the families that most patients have actually known their prognosis and it will be better to disclose the truth
- to tell families about the possible emotional reactions of patients and the way to support them

Family Centered Decision Making

Paternalism

Rational Non Interventional Paternalism

Family Centered Decision Making

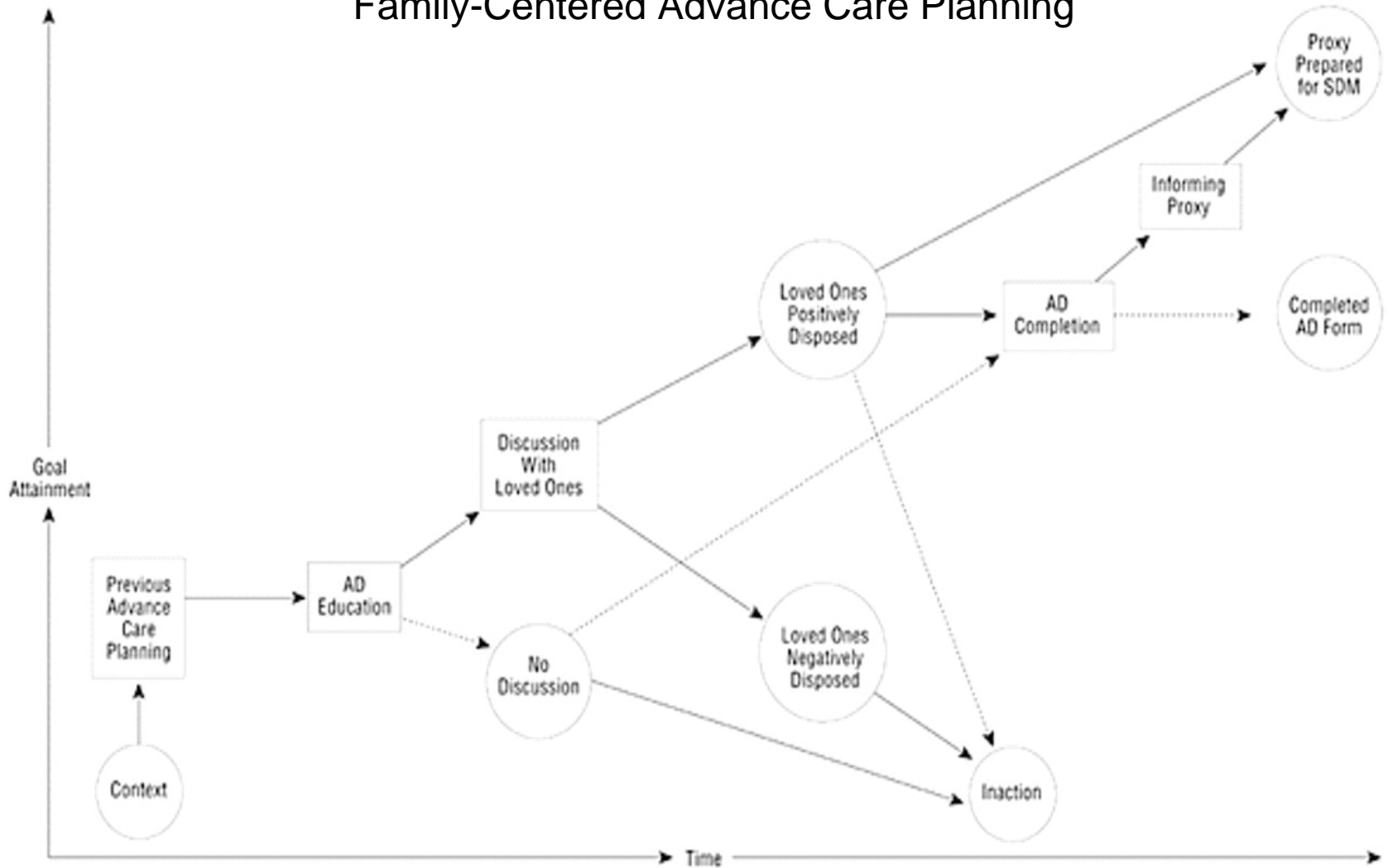
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Shared Decision Making

Fact Provider Model

Back, Psycho Oncol 2005;14:1052

Family-Centered Advance Care Planning



Singer, P. A. et al. Arch Intern Med 1998;158:879-884.

Case Presentation

- 49 yo woman with chest pain
- Post obstructive pneumonia, metastatic lung cancer
- Spoke Cantonese; primary translator was youngest son, age 22. He did not want to discuss diagnosis with patient, or allow MD to speak with patient through interpreters.

Muller West J Med 1992;157:323

Case Presentation

- 3 months – back pain, found to have epidural disease, received radiation
- 4 months – Patient and family refuse to discuss DNR
- 5 months – change in mental status, found to have brain metastases, Radiation
- 7 months – Family declined hospice
- 4 days later – new shortness of breath

Muller West J Med 1992;157:323

Case Presentation

- Patient had diffuse bilateral infiltrates, Admitted. Physicians decided against ICU
- HD 2 – patient worsened. Family refused DNR; attending writes DNR in chart. Family acquiesces.
- HD 2 - son kneels and demands intubation; refused; son charges bias and threatens litigation. Team re-examines workup/
- HD 3 – patient dies during family meeting. Son screams at medical team “You murderer!”.

Discussion Points

- Family Perspectives
- DNR orders
- Good Death
- Ethical correlates

Caregivers – The Family

Family Based Health Care

Family Relatives provide health care

Family relatives interact on behalf of the patient with the outside

Family expected to make the decisions

Benefits

- Continuity of care

- Informality

- Therapeutic effectiveness

Tong J Palliative Care 1994;Spring;10:26-8

Perspectives

Family

Protect the patient

Family duty

Patient survival

Filial piety

Doctors

Protect the patient

Professional duty

Patient quality of life

Breaking Bad News – End of Anticancer Treatment - Japan

Family distress at news

Very Distressed	(123)	39%
Distressed	(100)	31%
Slightly Distressed	(62)	20%
Not so distressed	(21)	6%
Not distressed	(12)	4%

Family perception of patient's response in 145

Very Distressed	(49)	34%
Distressed	(56)	39%
Mild to no distress	(40)	27%

Determinants of Family Reported Emotional Distress

<u>Variable</u>	<u>Multivariate analysis</u>	<u>p</u>
Patient age	0.97 [0.95--.99]	.014
Female	2.6 [1.5-4.7]	.001
“I can do nothing for the patient any longer”	2.1 [1.1-3.8]	.017
Willing to explore families’ feelings	0.59 [0.35-0.99]	.046
Prognosis of definite periods without ranges	4.3 [1.7-11]	.002

Morita Ann Oncol 2004;15:1551

Helpful Physician Behaviors

- Don't say "I can do nothing for the patient any longer"
- Explain treatment goals in specific terms
- Pace explanation with the state of the families' preparation
- Physician knowledgeable about the most advanced treatments
- Atmosphere allows for asking questions

Good Death

- Older patient (> 60 years old)
- Non violent death
- With immediate family members (song zhong)
- Peaceful

Barriers to End of Life Discussions

Death as a taboo subject

Discussion may hasten death

Discussion may insult the patient

Chinese culture values survival and endurance

好死不如惡活

Truth telling

Autonomy or “Assault with the truth”?

Ideas for EOL Discussions

Presented as part of a general plan of care

Presented as contingency planning

Appraisal of when CPR is indicated and when it is not

Reasons for DNR

Avoid further suffering

CPR as a violent death

Patient separated from family in CPR, ICU

Respect

Doctor ---- Patient
Hospital ---- Family
Medical Field ---- Culture

Ethical Issues

- Chinese

Respect

Confucian Ren

Buddhist Tzu-Bei

Principle Yi

Virtue De

- Western

Autonomy

Beneficence

Justice

DNR Orders in Taiwan

- 177 deaths in a Cancer Clinical Trials Unit in a teaching hospital from 4/1992-8/1997
- DNR orders written for 64% of patients; patients in pain more likely to have DNR
- Orders written with consent of family members
- Patients taken home to die for 30 pts (17%)
- CPR in 30 pts (17%) family insistence

Additional Discussion Points

- Suicide
- Pain Assessment

Suicide in Chinese Inpatients

Setting – Chang Gung Memorial Hospital, 1988-97

Number 75 self destructive events, M:F 1.4:1, 15 fatal
M:F 2:1

Medical diagnoses Malignancy (31%), Neurological (20%), COPD (13%), Heart Disease (8%), Liver Failure, DM (5%)

Time Midnight to 8 Am 35 (47%)

Day 8 am to 4 pm 30 (40%)

Evening 4 pm – MN 10 (13%)

Method Knife cut 26 (35%), Knife stabbing 13 (17%),
Drowning

Clinical Factors – previous suicide attempts, family discord, delirium, only 8 patients had Psych referral before attempt

Pain

Attitudes to Pain in Chinese History

In the third century AD, during the Three Kingdoms period, the eminent physician Hua To had developed an analgesic potion that he used perioperatively. One of his patients, the general Kuan Yu, was wounded by a poisoned arrow. He drank the potion and played chess as his bone was scraped clean and his attendants fainted. The ideal patient does not complain of pain and the ideal physician prescribes effective pain medication.

Opium War

The Opium War between the United Kingdom and China in 1840 led to the beginning of a century of humiliation for the Chinese, and distribution of opium in China, with attendant social problems until the 1940s. These historical experiences are an important background for understanding opiophobia in China.

Patient Barriers to Pain Management

Addiction	3 items
Tolerance	3 items
Side Effects	3 items
Fatalism	3 items
Be good patient	3 items
Distract MD	3 items
Disease progression	3 items
Fear of injections	3 items

Ward SE Pain 1993;52:319-24

Barriers to Pain Scores

	<u>USA</u>	<u>Taiwan</u>	<u>Hong Kong</u>
Addiction	2.20	2.94	2.46
Distraction	1.27	2.40	3.44
Fatalism	1.04	2.56	2.64
Good patient	1.11	2.04	2.77
Injection	1.68	3.21	2.72
Progress Dz	2.05	3.80	3.64
Time Interval		3.75	3.62
Tolerance	1.47	3.62	2.51
Worst Pain	4.2		7.6

Acta Anesthesiol Sinica 1997;35:201-8

Chung TK et al. Cancer Nursing 1999;22:196-203.

Pain Instruments in Chinese

- Brief Pain Inventory
- McGill Pain Questionnaire

Terms for Pain History in Cantonese

Stabbing	刺痛	waves	一陣陣
sore	酸軟	sudden	突發
crampy	抽搐	severe	劇痛
burning	灼熱	severe	痛到死
numb	麻痺	mild	微痛
explosive	爆炸		
cutting	刀割		

Convenience sample of 986 Hong Kong residents

Acta Anesthesiol Sinica 1998;36(4 Suppl):S1-11

Opioid Side Effects and Pain Management

Non Dose Limiting

Sedation 鎮靜

Nausea 惡心

Constipation 便秘

Dry mouth 口乾

Dose Limiting

Confusion 精神錯亂

Delirium 譫妄

Hallucinations 幻覺

Myoclonus 肌陣攣

Depression Instruments in Chinese

- Beck Depression Inventory
- CESD
- Geriatric Depression Scale
- Hamilton Depression Rating Scale
- Hospital Anxiety Depression Scale
- Zung Self Rating Depression Scale

Multisymptom Instruments in Chinese

- Memorial Symptom Assessment Scale
- MD Anderson Symptom Inventory
- McCorkle Symptom Distress Scale

Condensed Memorial Symptom Assessment Scale (CMSAS)

How much did this symptom bother or distress you in the past 7 days?

Symptom	Present	Not at All	A little Bit	Some What	Quite a Bit	Very Much
Lack of energy *	Y / N	0	1	2	3	4
Lack of appetite *	Y / N	0	1	2	3	4
Pain *	Y / N	0	1	2	3	4
Dry mouth *	Y / N	0	1	2	3	4
Weight Loss *	Y / N	0	1	2	3	4
Feeling drowsy *	Y / N	0	1	2	3	4
Shortness of breath *	Y / N	0	1	2	3	4
Constipation	Y / N	0	1	2	3	4
Disfficulty sleeping *	Y / N	0	1	2	3	4
Diffieiculty concentrating *	Y / N	0	1	2	3	4
Nausea	Y / N	0	1	2	3	4

How frequently did these sysptoms occur during the last week?

Symptom	Present	Not at all	Rarely	Occasionally	Frequently	Almost constantly
Worrying	Y / N	0	1	2	3	4
Feeling sad	Y / N	0	1	2	3	4
Feeling nervous	Y / N	0	1	2	3	4

Chinese Terms

Taiwan

PRC

Pain Management

疼痛治理

疼痛控制

Palliative Care

支持性治療

姑息治療

Terminal Care

臨終護理

晚期治療

Hospice Care

安寧照顧

臨終關懷

Palliative Care Hong Kong SAR

1982 First palliative care consult team

1985 Society for the Promotion of Hospice Care

1987 Palliative Care Units

1992 Bradbury Hospice established

1995 Certificate courses for hospice nurses

1997 Hong Kong Society Palliative Medicine and
Hong Kong Hospice Nurses Assn

1998 Specialty of Palliative Medicine

Palliative Care Taiwan

- National Death Act in Taiwan was passed in 2000 to protect the rights of the terminally ill and includes a regulation that requests health professionals to take the responsibility of disclosing the adequate information per the patients' wishes

Palliative Care PRC

- July, 1998 Tianjin Medical University Hospice Research Center founded
- October 1990 Tianjin Second Hospital Hospice Clinical Ward
- 1992 Western and Eastern Hospice Symposium
- Late 1990's – Chinese Journal of Hospice
- Jan 2001 – Li Ka Shing Foundation funds for hospice services at 20 major hospitals

Xue Y, Caring 2004;23:34-6

Palliative Care Singapore

- 1985 Developed as home care
- 1986 Hospice doctor from abroad
- 1990's No hospice care in hospitals
- 1996 Tan Tock Seng Hospital
- 1999 National Cancer Center

Department of Palliative Medicine –
Singapore General Hospital, outpt, consult
Goh Singapore Med J 2005;46:204

Quality of Life

- World Health Organization – physical, social, and family well being.
- Alternative approach – What makes life worth living?

Quality of Life

PRC

生存質量

生活數量

Hong Kong

生活質素

Taiwan

生活素質

Likert Terms in Chinese

	Taiwan	Hong Kong
Not at all	一點也不	完全沒有
A little bit	有一點	少少
Somewhat	有一些	普通
Quite a bit	相當多	相當多
Very much	非常的多	非常多

QOL Instruments in Chinese

- FLIC
- FACT
- EORTC QLQ-C30
- SF-36 and SF-12
- Chinese QOL instruments
- EQ-5D
- McGill QOL

Cultural Aspects FACT

Dimensions of QOL suggested by HK focus groups

Living environment – housing, residence

Family – harmonious, encouragement, companionship, care

Treatment related physical health

Happiness – no relapse, freedom from stress

Financial Status – money, work, friends

Other concerns – Food, Social Stigma

Yu CLM et al Cancer 2000;88:1715-27

Spirituality

Traditional Chinese World View

- Continuity of the family is first priority
- Proper care of one's parents is the most fundamental duty. Mourning period 3 years.
- Ancestors intercede for the living and act as intermediaries with higher powers.
- Proper observance of rituals for the dead is important for future good fortune.
- Chinese gods are the spirits of humans who led good lives, and have been successively promoted in rank by emperors.

Quality Palliative Care

Language

Hand off across different venues

Strong allied services

Geriatrics, Nursing Home

Psychiatry

Social Work

Chaplaincy

Community Relations/ Referrals

Conclusions

Continuity of traditions and concepts in Chinese culture

These principles are supportive of palliative care.

“Future generations will look at us, as we look at the past.”

- Preface Orchard Pavilion.