

END-OF-LIFE ISSUES: AN INTERNATIONAL PERSPECTIVE

Professor Colleen Cartwright, Director Aged Services Learning & Research Centre* Southern Cross University, Australia

Adjunct Professor, UNSW Medical Faculty, Rural Clinical School
colleen.cartwright@scu.edu.au

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Demographic Trends: International (U.N. World Population Prospects: 2006 Revision)

COUNTRY	65+ 2005	2050	80+ 2005	2050
Australia*	13.1%	24.3%	3.5%	9.3%
Canada*	13.1%	25.7%	3.5%	10.0%
Europe (all)*	15.9%	27.6%	3.5%	9.6%
US*	12.3%	21.5%	3.5%	7.8%
China**	7.7%	23.7%	1.2%	7.3%
Indonesia**	5.5%	18.6%	0.6%	4.0%
Malaysia**	4.4%	16.3%	0.6%	4.0%
Singapore***	8.5%	32.8%	1.5%	14.8%
Greece #	18.3%	31.7%	3.5%	11.1%
Italy #	19.7%	32.6%	5.1%	13.3%
Japan #	19.7%	37.7%	4.8%	15.5%

* & # 65+ <x 2; 80+ <x 3; ** 65+ x3-4; 80+ x6-8; *** 65+ x4; 80+ x10

Context

- Better living conditions/health care have led to increased longevity – this is a success story, and it has rightly been celebrated as such ; in Australia there are now over 3,000 people over 100; there are >18,000 over 100 in China; >26,000 in Japan and >78,000 in the US!
- Rapid technological development has allowed people who would previously have died to be kept alive for long periods of time, often through the use of such things as ventilators and feeding tubes.
- *But* these successes have also led to practical, legal & ethical issues, in particular around end-of-life care and extending the dying process.

Fear in the Community About the End of Life: Cases Reported

- Loved one “left hooked up to machines until the very end. We couldn’t even get close enough to give him a hug and say goodbye”.
- “Mum always said she wouldn’t want to be resuscitated if her heart stopped, but they wouldn’t listen”.
- (Wife) “First of all he was stubborn when he was in hospital; he wouldn’t eat - he was just starving himself. They couldn’t get him to eat ... so they had to force-feed him. They put a tube down his nose and then they had to tie him in the bed, because he kept pulling it out. He just didn’t want it”.

Community Concerns in Terminal Illness: Rank Order

FACTORS	Q1	Q2	NT
Loss of mental faculties	1	1	1
Loss of control	2	2	2
Loss of independence	*	3	3
Burden on family	*	4	4
Loss of dignity	4	5	5
Leaving loved ones	5	*	6
Protracted dying	*	*	7
Extreme ¹ /Physical ^{2,3} pain	3	6	8
Death itself	9/9	9/9	10/10

Advance Care Planning

- One mechanism to address community fears & concerns is Advance Care Planning (ACP), through use of Enduring Guardians (EG) & Advance Directives (AD).
 - 1990 US Patient Self-Determination Act; up-take was slow elsewhere
- 15 years ago, progressing ACP in Australia was like “trying to push bricks up-hill”, especially with medical practitioners; (“New ideas are first ignored, then resisted and finally accepted as self-evident”)

Advance Care Planning (Cont.)

- EG legislation was gradually enacted – much slower for AD
 - Michael Ashby & Jenny Abbey “led the charge” in SA in early 1990s;
 - Some other states/territories followed - still no specific AD legislation in NSW, WA or TAS
- However – “there is nothing so powerful as an idea whose time has come” (Victor Hugo)
 - In 2005 Federal Govt. introduced Respecting Patient Choices (after paying \$\$\$\$ to US!!)
 - in 2006 AMA endorsed use of ADs
 - UK enacted AD legislation 2007 (Mental Capacity Act)
 - Many countries incl. Canada, the Netherlands, Thailand (2007) and Mexico (2007) now have provision for Advance Directives and proxy decision-making
 - Several students presented on ACP at ERA on Tuesday!

Confusion About What is/is not Euthanasia

- Many problems stem from confusion over what is, or is not, euthanasia. This leads to:
 - Inadequate pain management
 - Inappropriate use of medical technology
 - Fear among health professionals of legal consequences of care provision
 - Poor doctor-patient communication
 - Disillusioned patients/families/carers

Common Beliefs

- Some commonly held beliefs are that euthanasia includes:
 - (a) giving increasing amounts of needed pain relief which may also have the effect of shortening the person's life; or
 - (b) respecting a patient's right to refuse further treatment; or
 - (c) withholding or withdrawing life support systems that have ceased to be effective or that will provide no real benefit to the patient
 - (d) providing a patient with the means to end his/her own life

None of these is euthanasia

(d is Physician-Assisted Suicide)

Definitions of Euthanasia

- The World Medical Association defines euthanasia as "the deliberate ending of a person's life at his or her request, using drugs to accelerate death".
- Definition used in studies by Cartwright et al:
 - Euthanasia is a deliberate act intended to cause the death of the patient, at that patient's request, for what he or she sees as being in his/her best interests (i.e. Active Voluntary Euthanasia – AVE).

Giving Pain Relief Which May Also Shorten the Patient's Life

- Often referred to as "the doctrine of double effect" - primary intention is to relieve pain, secondary, unintentional effect may be the hastening of the person's death.
- Accepted by most religious and medical groups, including those who strongly oppose euthanasia.
- Not giving adequate pain treatment when needed may shorten life: patients may suffer complications such as life-threatening cramps or severe respiratory problems if severe pain is left untreated

Respecting a Patient's Right to Refuse Treatment

- In Australia, this is a legal and moral right possessed by every competent person, under both common law and, in some States/ Territories, under statute law relating to assault; also by non-competent patient by AHCD or Enduring Guardianship.
- Difficult area for some health professionals to accept, especially such things as a person refusing a blood transfusion because of religious beliefs.

Withholding/Withdrawing Futile Life-Supports Systems

- Used to be called "passive euthanasia"; general agreement that that term is unhelpful - it can lead to the inappropriate continued use of invasive technology.
- Often it is not prolonging life, it is merely prolonging the dying process
- Removal of futile treatment is good medical practice. However, no definition of futility in law; generally agreed, when burden outweighs benefits – but "burden" and "benefit" should be from patient's viewpoint.
- Doctors more reluctant to withdraw than to withhold – morally, legally, ethically, no difference.

Confusion about Euthanasia -Italian Case

- December 2006 – Piergiorgio Welby, a paralysed muscular dystrophy patient, was denied the right to be removed from life support. Italian law allows patients to refuse care but not to have someone else remove life support machines (illogical and discriminatory).
- An anaesthetist who sedated him and turned off the respirator faced a Medical Board disciplinary hearing – cleared.
- Catholic Church in Italy refused the family's request for a religious funeral for Mr Welby – outraged many.
- Prosecutors reviewed the case for 2 months but decided doctor had supported the patient's constitutional rights

International Law

- NT Australia.; first place in the world to legalise both euthanasia (EU) and physician-assisted suicide (PAS) with *Rights of the Terminally Ill Act (1995)*; overturned by Federal *Euthanasia Laws Act (1997)*
- The Netherlands – EU and PAS legalised 2001
- Belgium - EU and PAS legalised 2001
- Oregon, USA – *Death With Dignity Act (1997)* legalised PAS, not EU
- Switzerland – assisted suicide is legal but not by doctors; person assisting must not stand to benefit
- Colombia, South America – in 1997 Constitutional Court "ruled 6-3 that an individual may choose to end his life and that doctors can't be prosecuted for their role in helping" – but no system established to implement this.

Concern Re: Ageing Populations and Abuse

- Presentation at Gerontology Congress Beijing Oct 2007
 - Attitudes Towards Euthanasia in Hong Kong
 - Euthanasia against the law
 - Withholding/withdrawing futile life-sustaining treatment acceptable
 - Study of "households" - 618 interviews conducted (46% response rate)
 - Majority support for Active euthanasia (AE) (2.64 on 5 point scale)
 - Reasons for attitudes:
 - Accept euthanasia if patient is old, or causing burden on family
 - Not worried about abuse
 - Have faith in medical system to implement euthanasia properly
 - Disagree with "treasuring life"
 - Higher age = more support for AE (opposite to Australia)
 - Higher income/education = more support (same as Australia)
 - Comment by presenter – possible explanation for public support for AE: "efficiency" is always emphasised in Hong Kong culture (!!!!)_

EURELD Study

- A cross-national comparison of medical decision-making at the end-of-life (MDEL) by physicians in 7 countries: Australia, Belgium, Denmark, Italy, the Netherlands, Sweden and Switzerland.
- Structured questionnaire mailed to medical practitioners working in specialties most likely to be involved with end-of-life care in the seven participating countries.
- Response rates: >60% in 4 countries, Belgium 58%, Australia 53% and Italy 39% (n=10,139).

Scenarios

- **Patient: aged 71 years; has cancer with extensive brain and bone metastases. Further chemotherapy not indicated.**
 - **Scenario 1:** Patient is clear-headed, can still communicate well. Estimated life expectancy no more than 2 weeks. Pain is difficult to control, despite high dose analgesics.
 - **Scenario 2:** Patient is clear-headed, can still communicate well. Estimated life expectancy at least 3 months. Pain adequately controlled, but patient is extremely tired, short of breath and bedridden.
 - **Scenario 3:** Patient is drowsy, sub-comatose, communication not possible. Estimated life expectancy no more than 2 weeks. Pain adequately controlled, but patient is extremely tired, short of breath and bedridden.
 - **Scenario 4:** Patient is drowsy, sub-comatose, communication not possible. Estimated life expectancy at least 3 months. Pain is difficult to control, despite high dose analgesics.

Action/Instigator

■ Actions: would you

- Give drugs, such as benzodiazepines or barbiturates, to keep the patient in deep sedation until death occurs? (& withdraw/withhold artificial nutrition/hydration)
- Administer drugs with the explicit intention of hastening the patient's end of life? (euthanasia)

■ Instigator

- At request of patient (current request Sc1/2/ through Advance Health Care Directive Sc3/4).
- At request of relatives (without first informing patient - Sc1/2 only)
- On own initiative to prevent further suffering

Give drugs to keep patient in deep sedation until death occurs –
% Yes/Probably: Competent Ptnt; Sc1: 2 wks to live; pain
Sc2: 3 Mths to live; Pain controlled, tired, short of breath, bed bound

COUNTRY	Max N	Ptnt's Request		Rel's Request		Own Initiative	
		SC 1	SC 2	SC 1	SC 2	SC 1	SC 2
Australia	1478	63	40	8	4	26	14
Belgium	1750	83	54	24	11	39	18
Denmark	1217	52	22	10	2	25	8
Italy	1508	72	44	31	14	51	25
Netherlands	1275	70	34	2	0	11	4
Sweden	1514	55	29	6	1	22	9
Switzerland	1397	76	45	10	4	32	17
TOTAL	10,139	68	39	22	6	30	14
χ^2_6 p value		513.462 <0.0001	427.117 <0.0001	2049.886 <0.0001	486.88 <0.0001	676.439 <0.0001	359.191 <0.0001

Give drugs to keep patient in deep sedation until death occurs –
% Yes/Probably: Non-Competent Ptnt; Sc3: 2 wks to live; Pain controlled,
tired, short of breath, bed bound; Sc4: 3 Mths to live; pain

COUNTRY	Max N	Ptnt's Request		Rel's Request		Own Initiative	
		SC 3	SC 4	SC 3	SC 4	SC 3	SC 4
Australia	1478	73	69	55	50	55	50
Belgium	1750	86	85	60	55	63	60
Denmark	1217	58	49	39	32	46	38
Italy	1508	66	68	45	46	56	59
Netherlands	1275	78	71	38	40	39	35
Sweden	1514	56	48	31	28	38	35
Switzerland	1397	72	75	43	45	51	56
TOTAL	10,139	70	67	45	43	50	48
χ^2_6 p value		500.446 <0.0001	737.629 <0.0001	383.687 <0.0001	345.025 <0.0001	312.368 <0.0001	449.796 <0.0001

Give drugs to intentionally hasten patient's death –% Yes/Probably:
Competent Ptnt; Sc1: 2 wks to live; pain
Sc2: 3 Mths to live; Pain controlled, tired, short of breath, bed bound

COUNTRY	Max N	Ptnt's Request		Rel's Request		Own Initiative	
		SC 1	SC 2	SC 1	SC 2	SC 1	SC 2
Australia	1478	24	15	2	1	9	5
Belgium	1750	54	41	5	2	13	6
Denmark	1217	23	11	3	1	12	5
Italy	1508	14	9	2	1	5	2
Netherlands	1275	59	43	0	0	5	2
Sweden	1514	6	5	1	1	2	2
Switzerland	1397	24	18	1	1	8	5
TOTAL	10,139	29	21	2	1	7	4
χ^2_6 p value		1687.435 <0.0001	1289.428 <0.0001	122.35 <0.0001	29.045 <0.0001	201.756 <0.0001	75.267 <0.0001

Give drugs to intentionally hasten patient's death –% Yes/Probably:
Non-Competent Ptnt; Sc3: 2 wks to live; Pain controlled, tired,
short of breath, bed bound; Sc4: 3 Mths to live; pain

COUNTRY	Max N	Ptnt's Request		Rel's Request		Own Initiative	
		SC 3	SC 4	SC 3	SC 4	SC 3	SC 4
Australia	1478	27	26	15	13	19	16
Belgium	1750	59	60	26	26	28	28
Denmark	1217	26	23	12	12	20	17
Italy	1508	13	13	4	4	6	7
Netherlands	1275	50	55	13	15	12	10
Sweden	1514	8	9	3	2	5	4
Switzerland	1397	28	29	9	10	13	15
TOTAL	10,139	31	31	12	12	15	14
χ^2_6 p value		1503.838 <0.0001	1656.206 <0.0001	557.989 <0.0001	578.964 <0.0001	503.759 <0.0001	496.816 <0.0001

Medical Practitioner Characteristics

- Additional analysis found some differences between respondents by age, gender, religion and belief but these were not as strong as differences by country.
- Support for patient autonomy appears to be strongest in Belgium and the Netherlands, followed by Switzerland and Australia but for the former this may also reflect the legal situation in those countries.



Healthy Ageing: Healthy Dying

- An ageing world population brings many challenges – including the imperative to protect our most vulnerable older people
- When older people not only live well but also die well, we can claim success!

Thank You