

**Do we really know  
what our patients want  
and do we respect it?**

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# What are we talking about?

- A 76 yo father with disseminated cancer with progressive pneumonia in ICU on a ventilator after a MET call
- A 93 yo mother with dementia, from a nursing home, in hospital for 6 weeks with # NOF
- An 84 yo mother, bedbound & unable to speak after a stroke, heading for a PEG and NH that she has told her family she doesn't want
- A 62 yo father with advanced cancer, who has requested NFR, but is resuscitated no form is completed

# What is advance care planning?

... 'a process, whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he/she become incapable of participating in medical treatment decisions'.

*P Singer et al 1996*

- Ethical principles
- autonomy
  - informed consent
  - beneficence vs non-maleficence
  - dignity
  - prevent suffering

# Why is advance care planning important?

Most people (~ 85%) will die after chronic illness, not a sudden event

Nearly half of us are not in a position to make our own decisions when we are near death

Our family have a significant chance of not knowing our views without discussion

A doctor who is uncertain about what to do, and who has to make a decision, will often treat aggressively

Many of us will be kept alive under circumstances that are not dignified, frequently suffering and in a way that we would not have wanted

# The aims of advance care planning

- *Initiate conversations with adults regarding views about future medical care*
- *Assist individuals with advance care planning*
- *Make sure plans are clear*
- *Ensure plans are available*
- *Appropriately follow plans*

# Respecting Patient Choices (RPC)

- An Australian advance care planning program
- Commenced in 2002
- DoHA funding
  - Multiple aged care facilities
  - Community palliative care services
  - Pilot sites in each state and territory
- Victorian Department of health
  - 8 Victorian health services (Austin, Northern, Eastern, Southern, Alfred, Peninsula, Barwon, Warnambool)
  - Statewide ACP policy

# Case study of Patient AG

## Patient Background

81yo man lives with wife, diagnosed with lung fibrosis in July 2004, and treated with steroids and oxygen. Poor response to treatment with increasing breathlessness, and increasing oxygen requirements.

## Respecting Patient Choices

RPC was introduced.

- At his initial contact in July 2004 he declined.
- In January 2005 he was approached again, and he was able to state some of his wishes, including:
  - Not for intubation
  - Not for ICU and other aggressive management

# AG Continued .....

- He discussed his wishes with his GP, and these were documented on the discussion card, but he did not complete a MEPOA (was in process of doing this) or SOC.
- He subsequently became acutely breathless at home and asked his wife to ring GP, not ambulance (as he would have previously done).
- His GP attended him and provided comfort care at home and he died.

## The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

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### ABSTRACT

**Objective** To investigate the impact of advance care planning on end of life care in elderly patients.

**Design** Prospective randomised controlled trial.

**Setting** 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.

**Interventions** Participants were randomised to receive

decisions,<sup>1-3</sup> resulting in patients being cared for in a way they would not have chosen.<sup>2</sup> This has continued to the present day.<sup>4</sup> Apart from progress in palliative care, the main focus to deal with these needs has been the development of advance care planning. Advance care planning is a process “whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions.”<sup>5</sup> The

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# Randomised controlled trial

- English speaking, competent patients aged  $\geq 80$ YO, admitted to hospital
- Intervention – ACP using the RPC model
- Primary outcome
  - compliance with patients EOL wishes
    - **Wishes known & respected**

# Randomised Controlled Trial (Aug 07 – Mar 08)

1044 files / patients reviewed



877 individual patients



309 patients - informed consent obtained (35%)

154 intervention, 155 control

Excluded patients

- **not competent**, NESB, Prior ACP,
- expected to be discharged or die ,
- no family, refused

# ACP patients (n=154)

- 80% Completed ACP
  - 38% appointed SDM + wishes
  - 32% Wishes alone
  - 15% SDM alone— ½ left doctor to decide
- Family involved – Yes in 74%
- Average time taken - 64 minutes

# What decisions were made?

- On CPR and life prolonging treatments
  - Before discussions, 30 to 45% said no
  - After discussion:
    - » “yes” changed to - “yes depending on outcome”
    - “I delegate the decision”
    - less “don’t know”
- Requests “If I become very unwell”
  - for palliation and no aggressive treatment
  - call my family, the priest, don’t let me suffer

# Deceased patients

- 56 patients (18%) died within 6 months
  - 29 intervention, 27 control patients
- Patient's wishes known and respected
  - Intervention 86%
  - Control 30%  $p < 0.001$
- No difference in mortality between groups
- Location of death
  - Acute hospital: 16 in both groups
  - ICU: 0 intervention pt, 4 control pt ( $p = 0.03$ )

# Patient / family feedback

- Discharge questionnaire
  - Control patients- negative comments
    - *the doctors don't listen*
    - *I felt ignored and in the way*
    - *They don't want me as I am too old*
    - *They wouldn't speak to me, and kept discussing things with my family*

# Impact of death on surviving relatives

- Death of a relative can cause significant anxiety, depression and post-traumatic stress
  - Azoulay E, et al. *Am J Resp CCM*2005;171:987-94
  - Lautrette A, et al. *N Engl J Med* 2007;356:469-78
  - Wright AA, et al. *JAMA* 2008;300:1665-73.
- How do you quantify the impact?
  - IES: Impact of Event Score
  - HADS: Hospital Anxiety & Depression Score

# Deceased patients (56 patients)

	<b>Intervention</b>	<b>Control</b>	<b>P value</b>
IES score: median, IQR	5, 2-5.5	15, 5-21	<0.001
Number of people with IES > 30	0	4	0.03
HADS depression: median, IQR	0, 0-1.5	5, 0-9	<0.001
Number of people with HADS – depression > 8	0	8	0.002
HADS anxiety: median, IQR	0, 0-3.5	3, 0-6	0.03
Number of people with HADS – anxiety > 8	0	5	0.02
FM's satisfaction with the quality of death			0.02
Very satisfied: n, %	24, 82.8%	13, 48.1%	
Satisfied: n, %	2, 6.9%	8, 29.6%	
Not satisfied, n. %	3, 10.3%	6, 22.2%	
FM's perception of patient's satisfaction with the quality of death			<0.001
Very satisfied: n, %	25, 86.2%	10, 37.0%	
Satisfied: n, %	1, 3.4%	10, 37.0%	
Not satisfied, n. %	3, 10.3%	7, 25.9%	

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# Deceased questionnaire

## Intervention group

- *He had a very peaceful death, just as it should have been, & I would like to thank all staff for this.*
  - *Even though we already knew what he wanted it was great to be able to talk about it so openly.*
- 

## Control group

- *Mum didn't want heroics. I was horrified to hear she received 45 minutes of CPR. She didn't want it. All anyone had to do was ask.*
- *The doctors kept asking if dad should be resuscitated. I didn't think they should keep asking, as they also told us it wouldn't help him. It was obvious to us he was dying.*

# Conclusions from randomised controlled trial

- First RCT - coordinated ACP improves EOL care
- No difference in mortality
- Success of the RPC model (5 key elements)
  - Trained non-physician facilitators
  - Patient centred discussions
  - Involvement of family
  - Correctly filed documentation
  - Systematic doctor education

# Benefits of ACP

- ACP improves EOL care and patient satisfaction
- ACP assists family to:
  1. know patient wishes, be involved in ACP discussions
    - More able to make decisions
    - Less burdened
  2. Have less risk of stress, anxiety and depression
  3. Be more satisfied with quality of patient's death

# RPC in 17 local RACFs in 2004-05

- 1108 residents
  - Of those introduced, only 2% refused further discussion
- 16% of residents died during the 2 year evaluation
- 58% of the deceased residents had been introduced to RPC
- Of these, 89% had advance care plans (ACP)
  - cf 42% of those not introduced to RPC ( $p < 0.0001$ )
- 96-100% of their wishes were respected at EOL
- Likelihood of dying in hospital is much greater without RPC introduction: 46% vs 18% ( $p=0.0002$ )
- Greater satisfaction from residents, family, staff & GPs

# What was the GP involvement?

- GP involvement was encouraged, not mandatory
  - signed / witnessed 49% of 296 advance care plans
  - witnessed 60 MEPOAs
  - recorded advance care planning in 90 clinical records
  - actively participated in discussions with residents, NOK
- Involvement was more organised in some RACFs
  - benefit of aged care program managers
- Varied between GPs

# What was the GP feedback?

- “this program is long overdue”
- “of practical value...involves the RACF staff in discussion”
- “clarity of a resident’s wishes made decision making with the family much easier”
- “the GP information kit is very useful”
- “avoids residents being sent to hospital for EOL care”
- “young doctors [in hospitals] need to understand that people die with fatal [sic] illnesses and that they should die with dignity.”

# Where are we now?

- Developed model for implementation in RACFs across Australia
  - NHHRC recommendations
  - Productivity Commission: Caring for Older Australians
- ACP in community aged care, CALD and ATSI
- Research on ACP in:
  - Dementia/Alzheimer's
  - Mental health
  - Chronic disease

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