Advance Care Directives
Let Me Decide: an update on recent research

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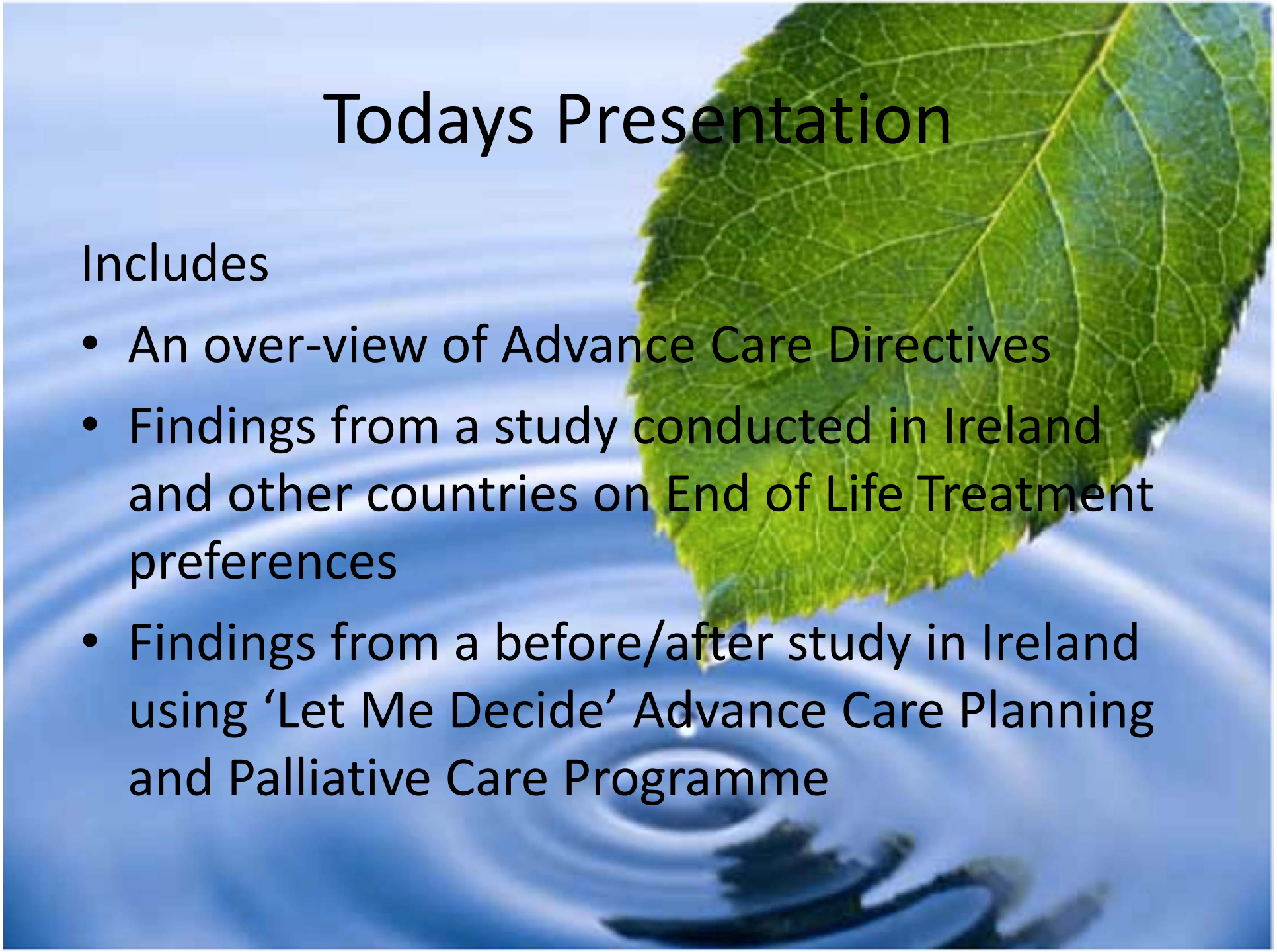
Centre for Gerontology and Rehabilitation, University College Cork

Ireland



Todays Presentation

Includes

- An over-view of Advance Care Directives
- Findings from a study conducted in Ireland and other countries on End of Life Treatment preferences
- Findings from a before/after study in Ireland using ‘Let Me Decide’ Advance Care Planning and Palliative Care Programme

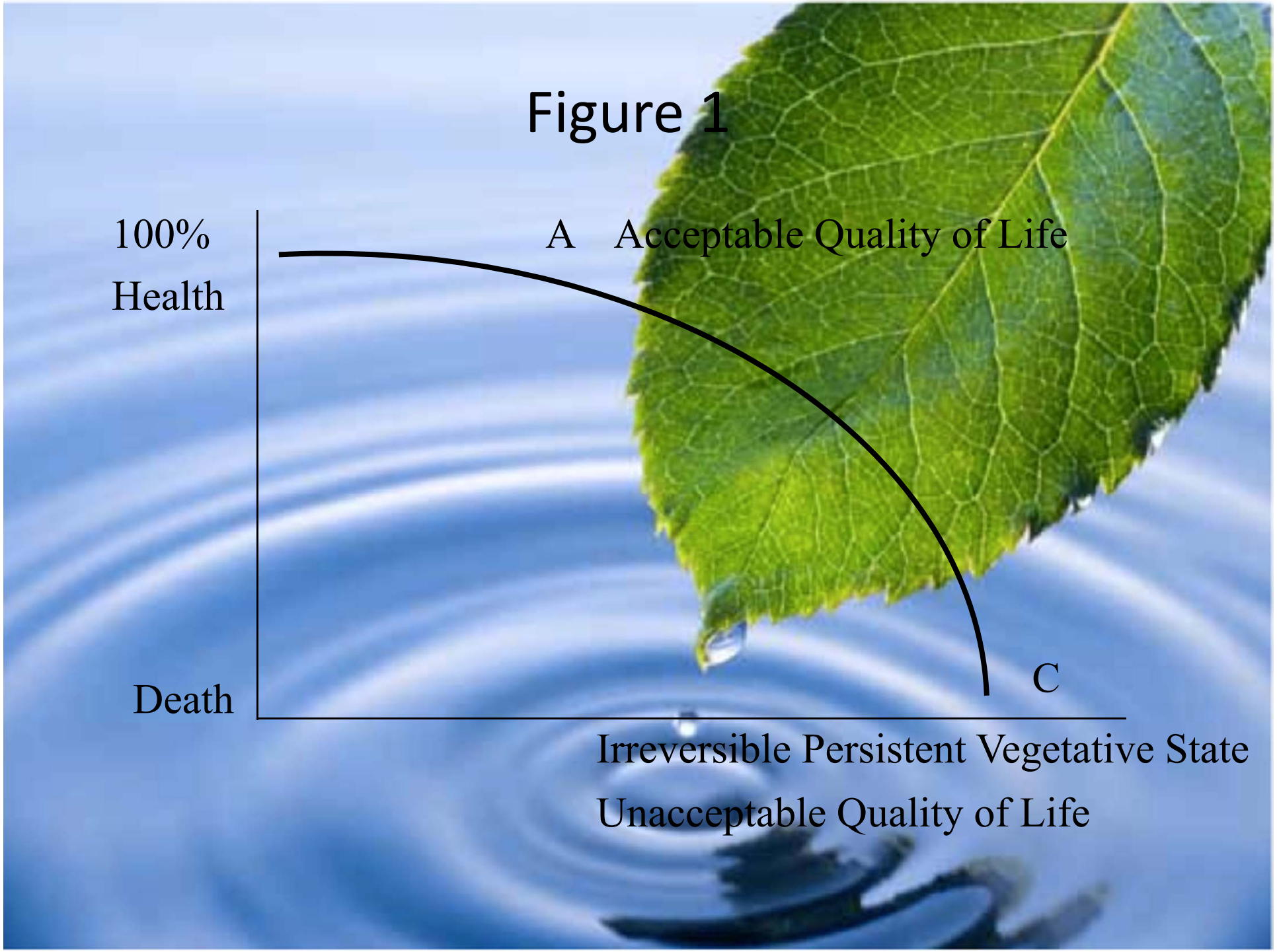
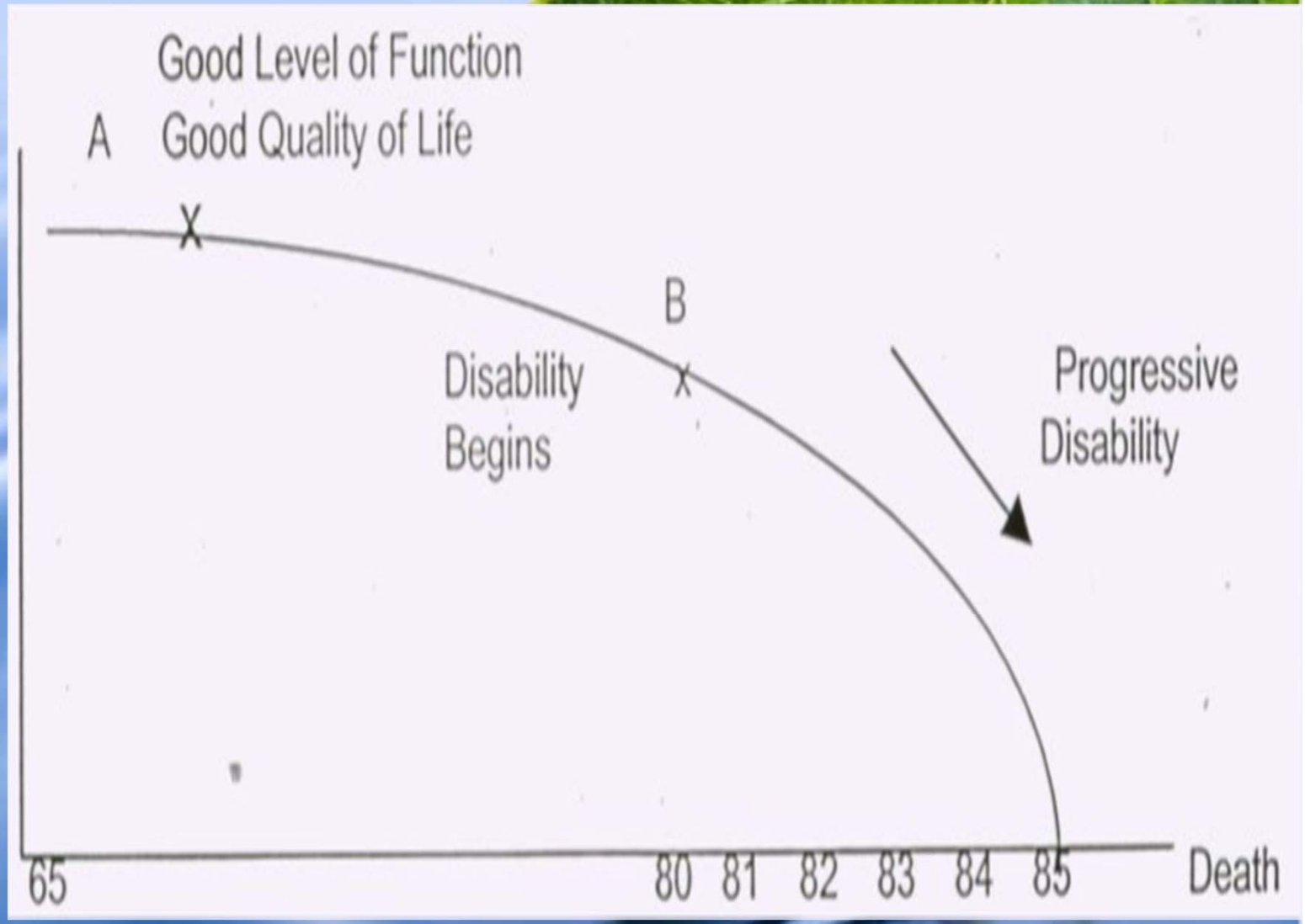


Figure 1
100%
Health
A Acceptable Quality of Life
C
Death
Irreversible Persistent Vegetative State
Unacceptable Quality of Life

Figure 2


Good Level of Function
A Good Quality of Life
100%
Health
Disability
Death
Disability
Begins
B
Progressive
Disability
65
80
81
82
83
84
85
Death

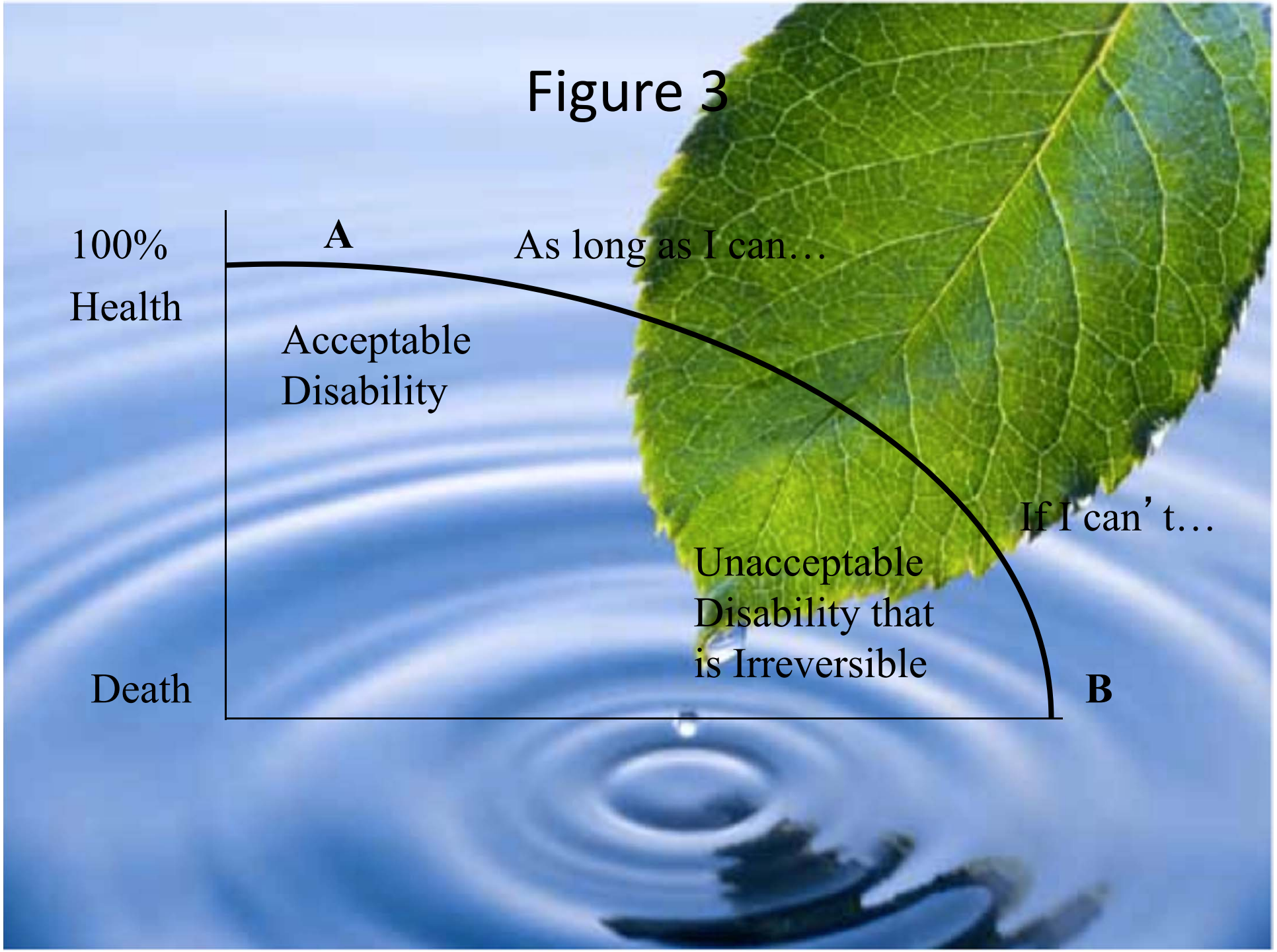
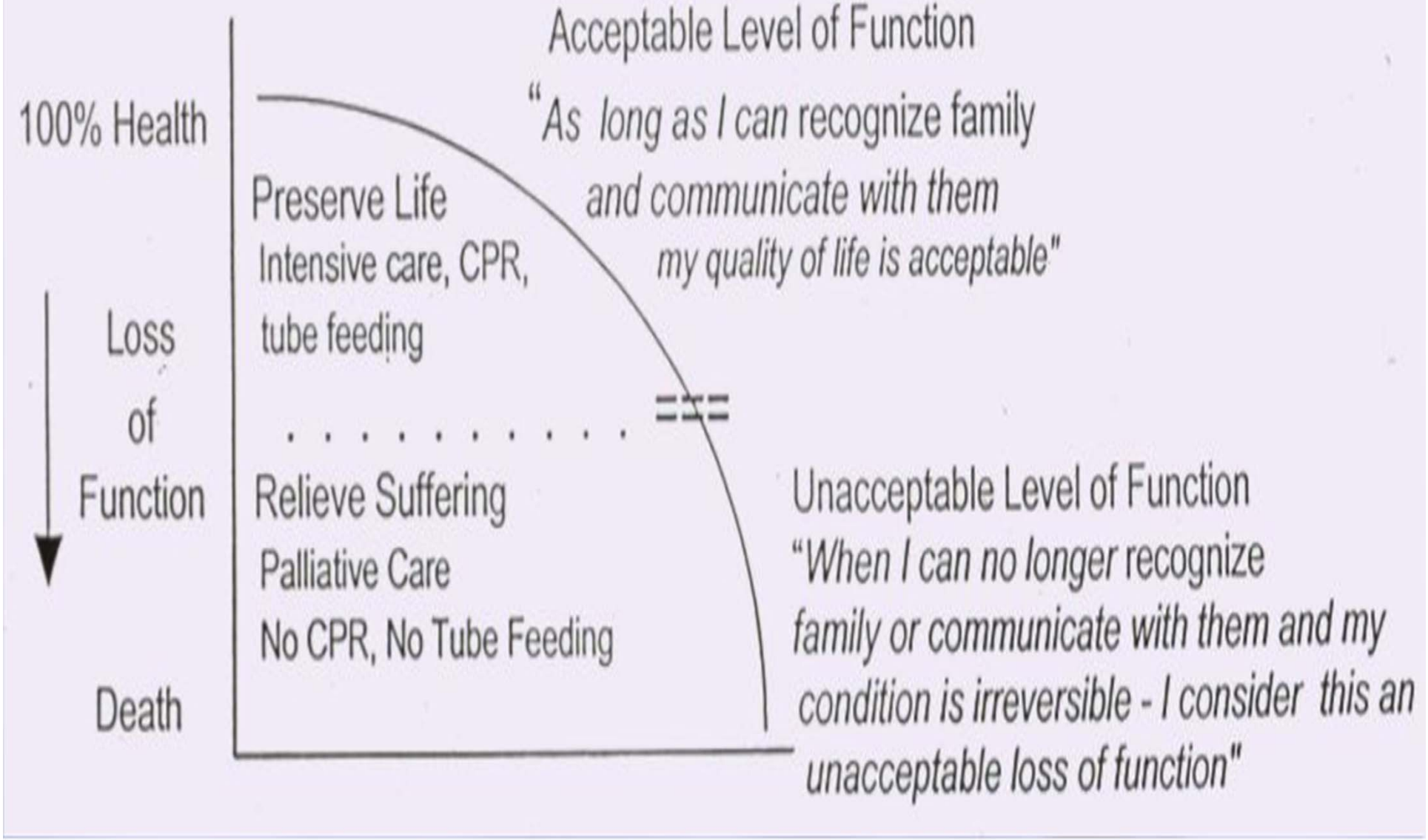


Figure 3
100%
Health
A
As long as I can…
Acceptable
Disability
If I can't…
Unacceptable
Disability that
is Irreversible
Death
B

Fig. 4 Defining the Irreversible condition with an:



Let Me Decide

Let Me Decide has 2 components: **Proxy** and **Instructional**

- **Proxy** component allows individuals to name another to speak on their behalf in the event of future incapacity
- **Instructional** component allows individuals to choose treatments for specific conditions

Let Me Decide Advance Care Directive

1. Summary of Patient Treatment Choices

In my CURRENT state of health/ functioning *if I became seriously ill* I would choose:		
Life-Threatening Illness	**Cardiac Arrest**	**Feeding**
Palliative Care Limited Care Surgical Care Intensive Care	No CPR CPR	Basic Tube

Let Me Decide Advance Care Directive

1. Summary of Patient Treatment Choices

IF I had an *Unacceptable/Irreversible* condition of health/ functioning and *if I became seriously ill* I would choose:		
Life-Threatening Illness	**Cardiac Arrest**	**Feeding**
Palliative Care Limited Care Surgical Care Intensive Care	No CPR CPR	Basic Tube

Palliative Care

- Only measures that enhance comfort or minimize pain; e.g. morphine
- Intravenous line started only if it improves comfort; e.g. hydration
- No X-Rays, blood tests or antibiotics, unless they are given to improve comfort
- Do not transfer to hospital unless absolutely necessary

Limited Care

- IV therapy may be appropriate
- X-Ray examination and blood tests may be appropriate
- A trial of appropriate drugs may be used; antibiotics should be used sparingly
- No invasive procedures; do not transfer to ICU
- May or may not transfer to hospital

Surgical Care

- Do not admit to ICU
- Do not ventilate (except during and after surgery)
- Emergency surgery if necessary
- Transfer to acute care hospital (where patient may be evaluated)

Intensive Care

- Transfer patient to ICU if necessary
- Ventilate patient if necessary
- Insert central line
- Transfer patient to acute care hospital without hesitation
- Provide surgery, biopsies, all life-support systems and transplant surgery

Cardiac Arrest

No CPR:

Make no attempt to resuscitate

CPR:

Use cardiac massage and artificial/mechanical breathing; may also include:

- endotracheal tubes
- defibrillation
- intravenous fluid and drugs

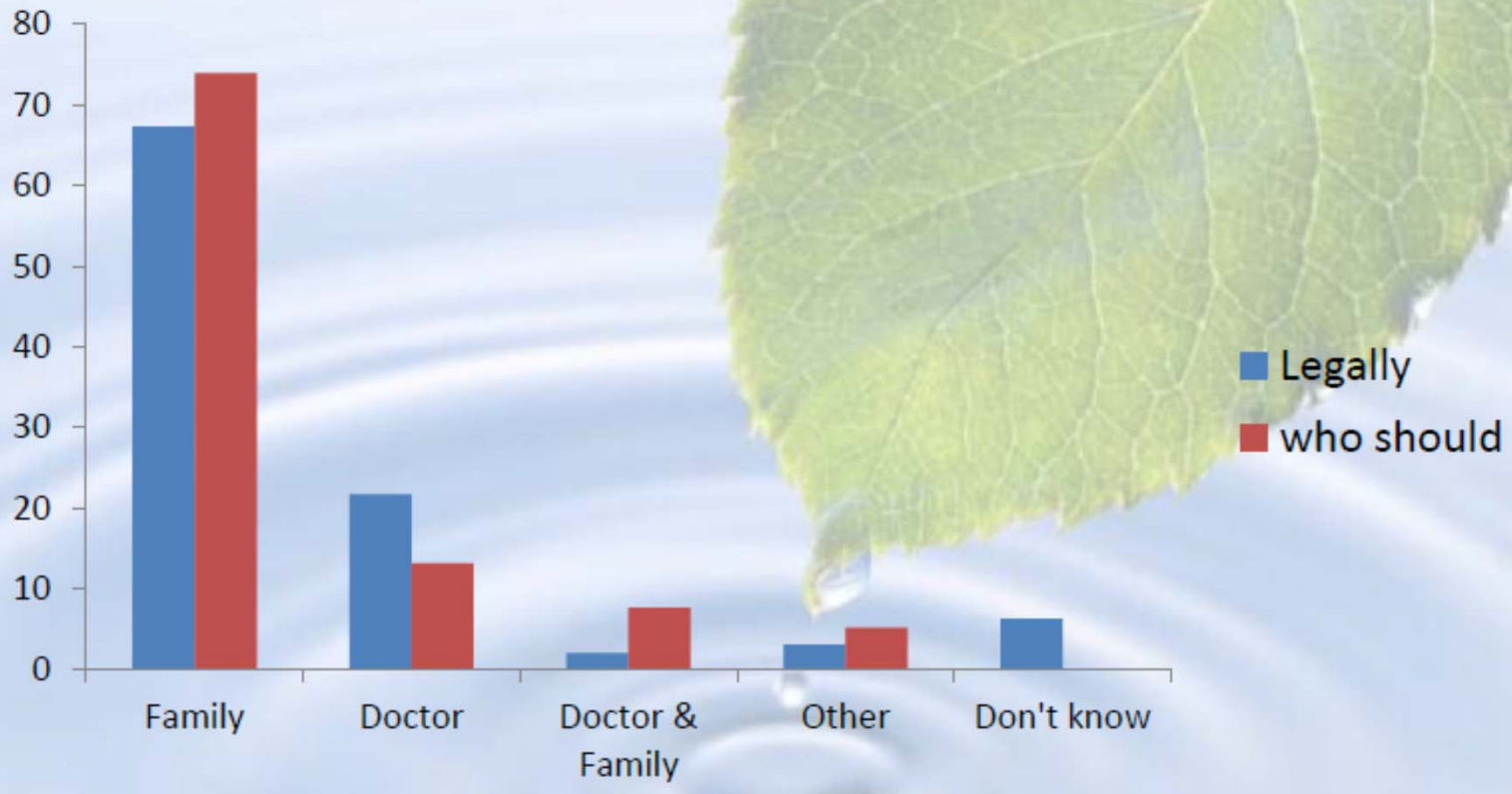
Health Care Professionals own Wills or ACDs

Irish public's awareness of end-of-life terms

Terminology	Know a great deal (%)	Know a fair amount (%)	Know just a little (%)	Heard of but know nothing (%)	Never heard of (%)
Advance directive	1	2	13	13	71
Living Will	10	15	28	15	31
DNR order	13	16	32	13	25
CPR	17	34	49	11	9
Post-mortem	23	33	33	6	4

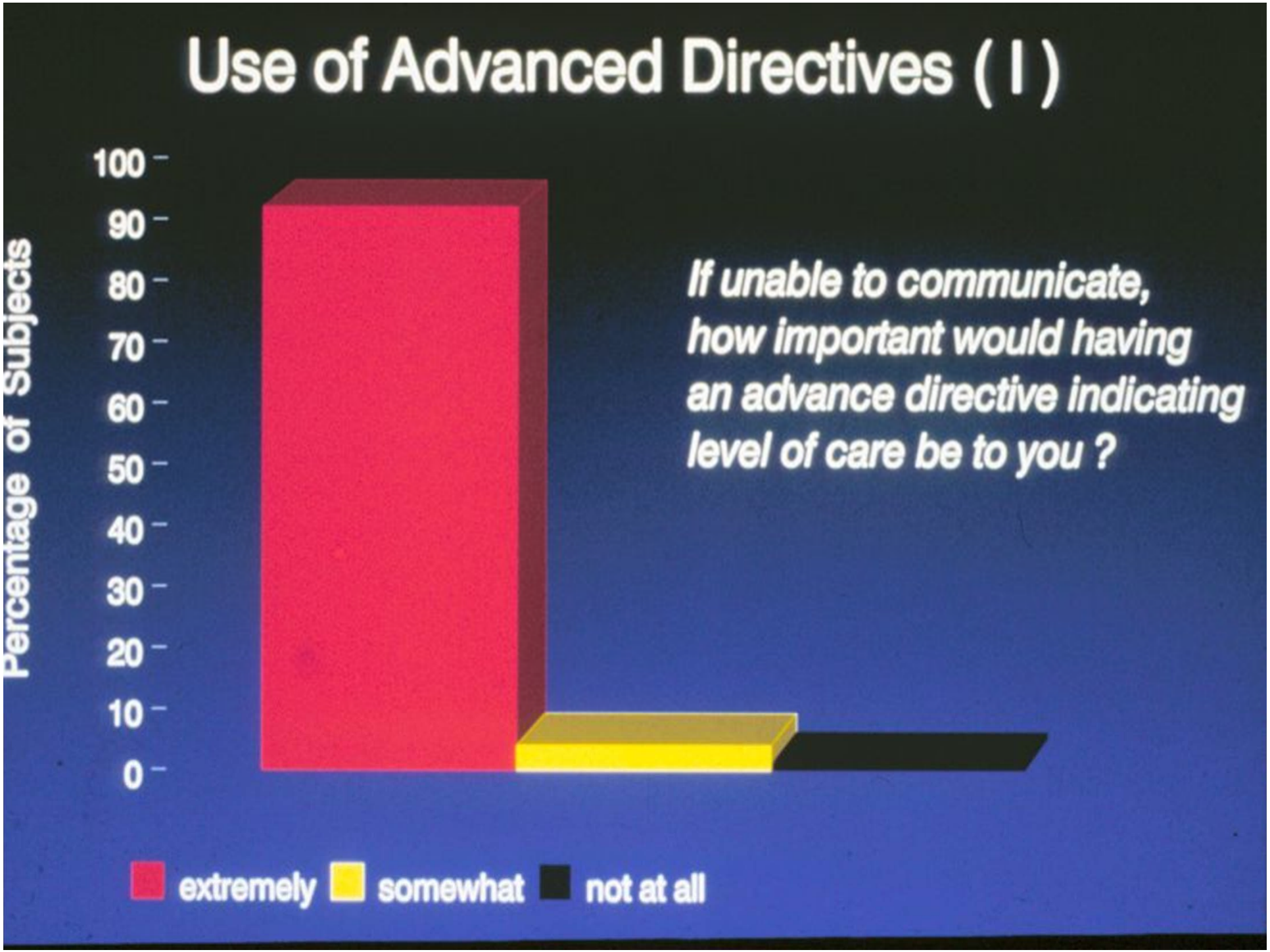
J McCarthy et al. *J Med Ethics* 2010 36: 454-458

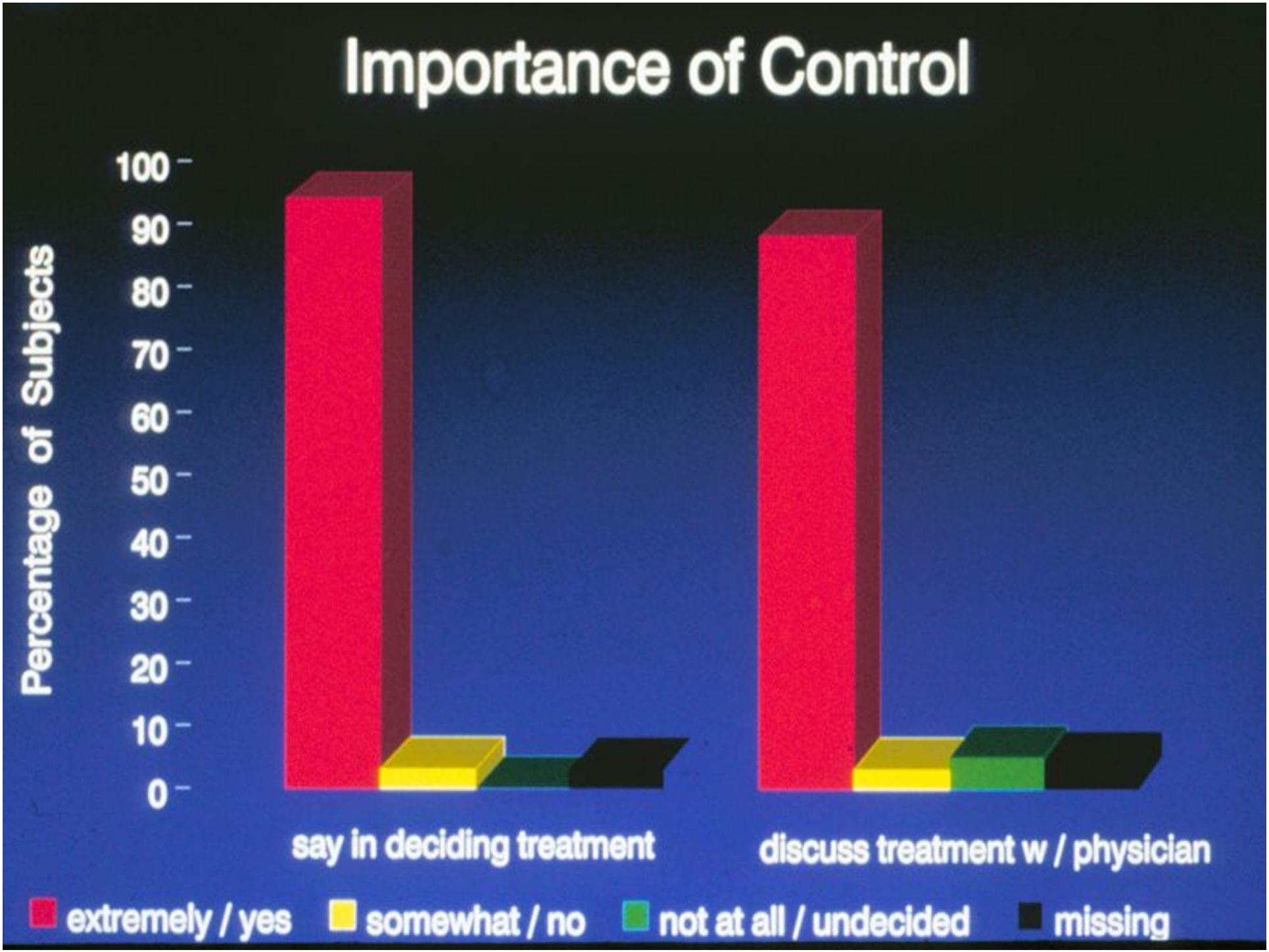
Who do Irish Healthcare professionals want to decide for them? 2012



Only 26% of Irish HCPs correct as to who legally decides (n=474)
Of the docotrs, only 35% of correct (n=165)

Use of Advanced Directives (I)

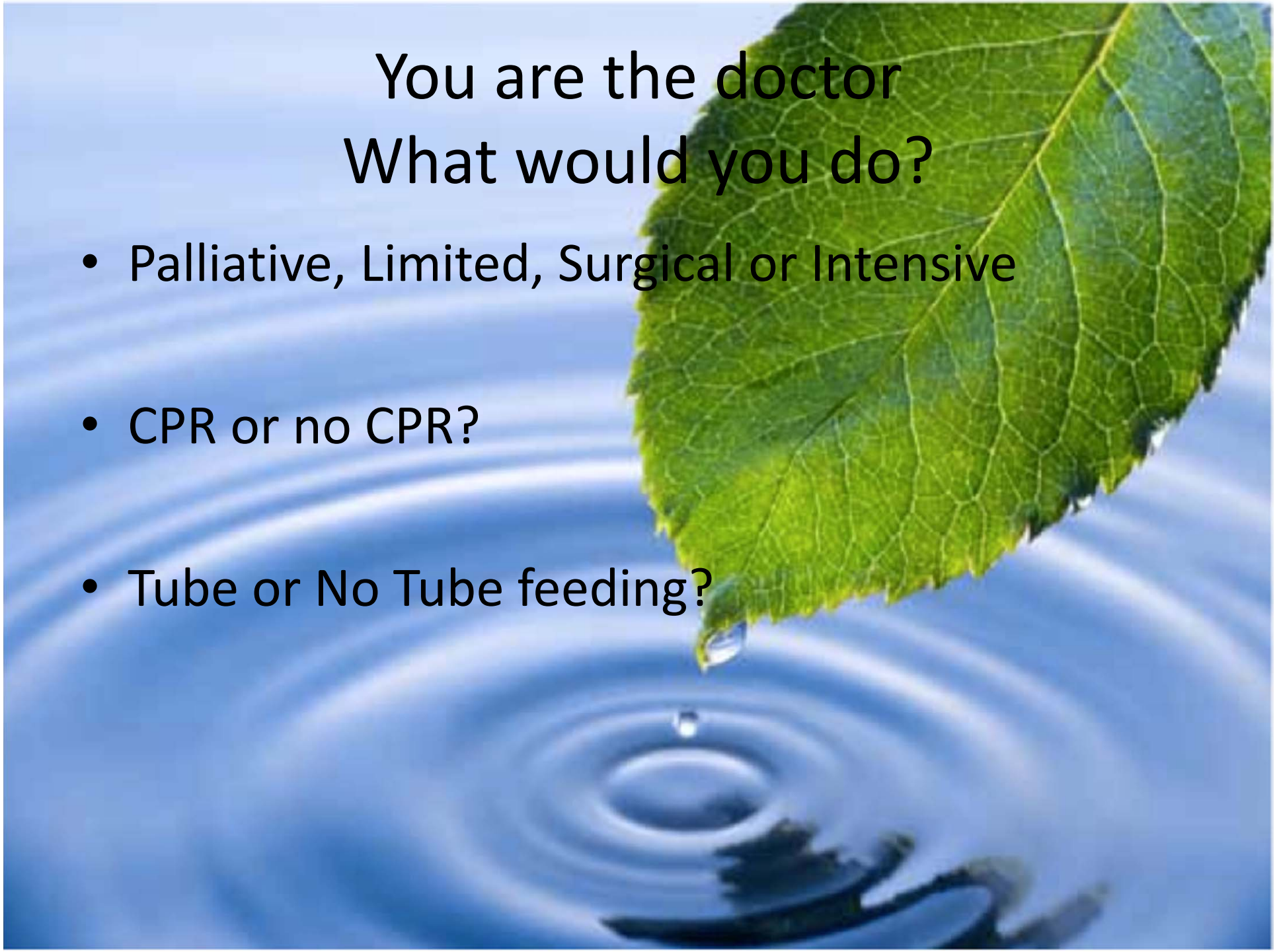



Importance of Control
Percentage of Subjects
100
90
80
70
60
50
40
30
20
10
0
say in deciding treatment
discuss treatment w / physician
extremely / yes
somewhat / no
not at all / undecided
missing

PATIENT CASE SCENARIO: MR MURPHY

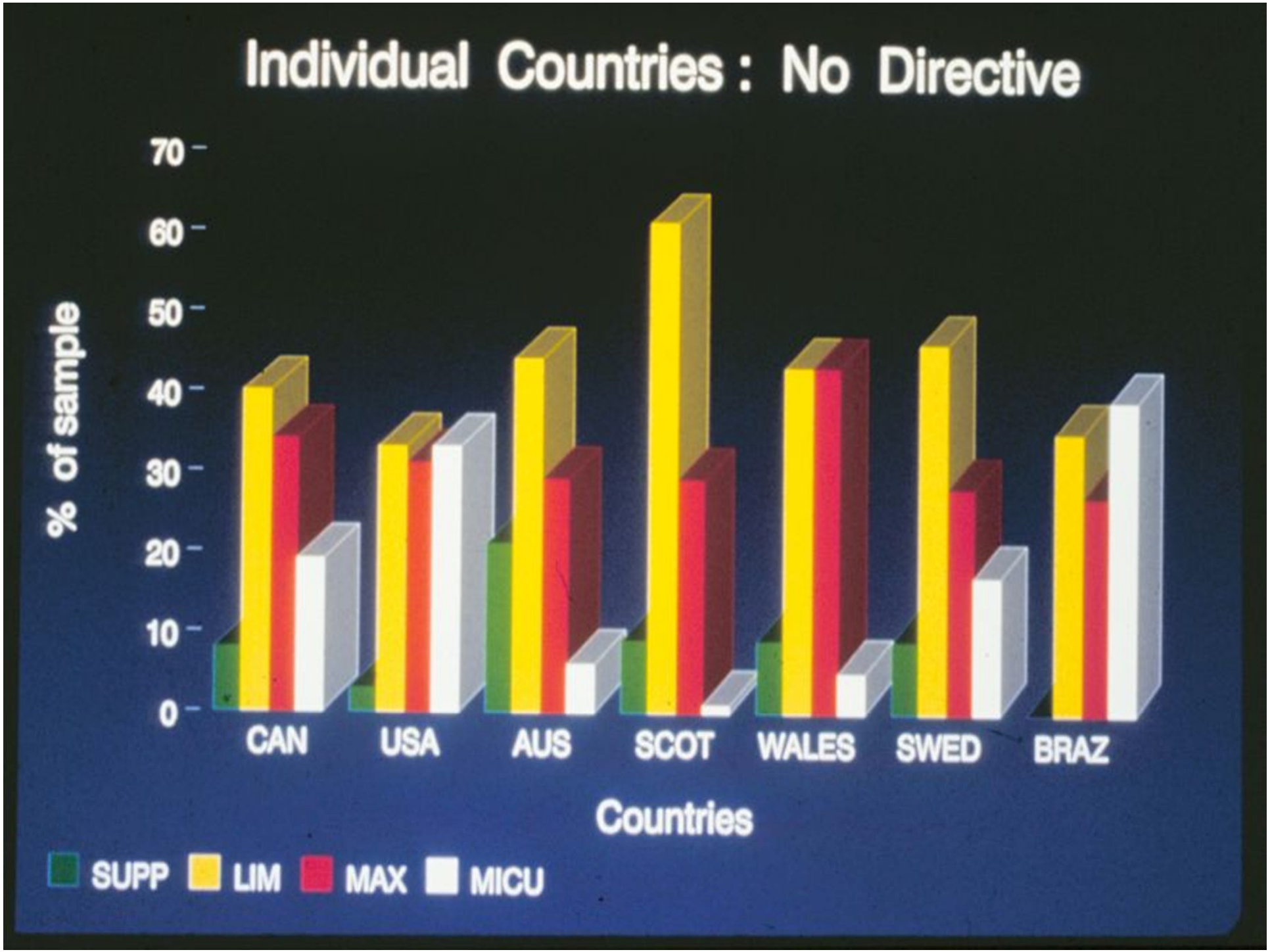
- 84yrs old
- Living in a nursing home
- Has Alzheimer's Disease for 7yrs
- Unable to recognise children, sometimes recognises wife
- Needs assistance with mobilising
- Incontinent

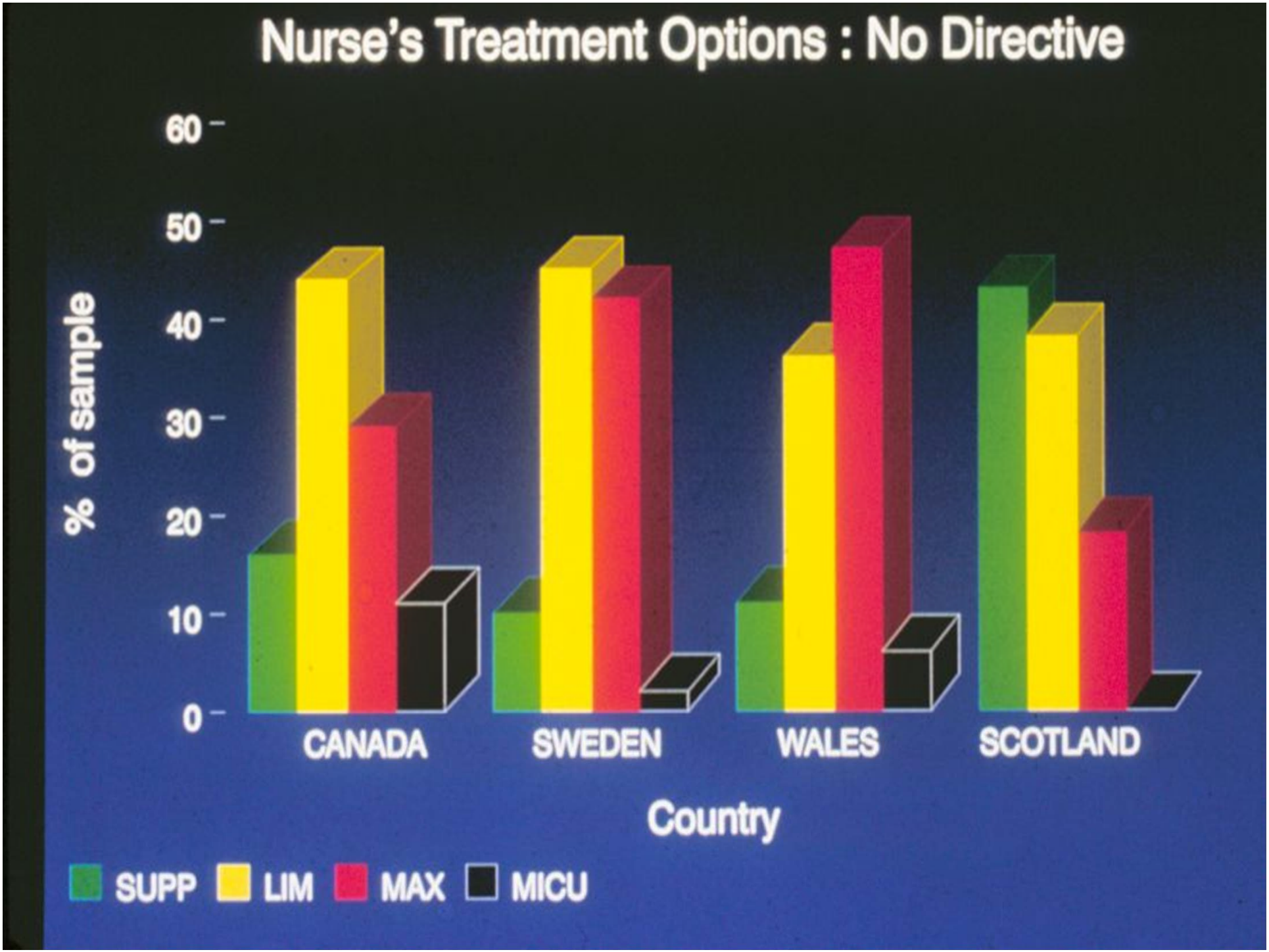
Mr Murphy is in the Emergency Department, has hematemesis and is hypotensive. Unless treated he will most likely die. His family are not available and there is no advance directive. What would you do?

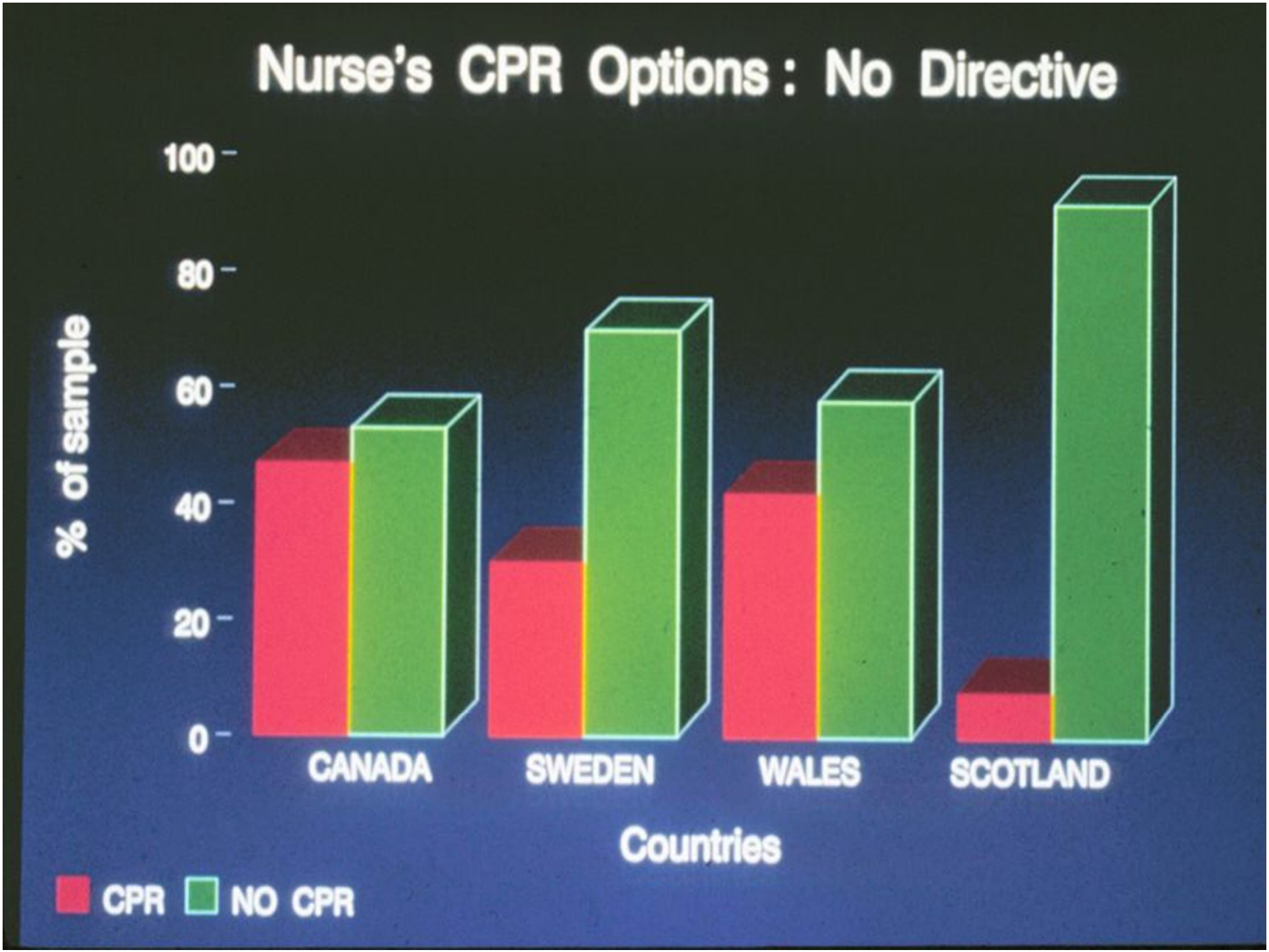


You are the doctor
What would you do?

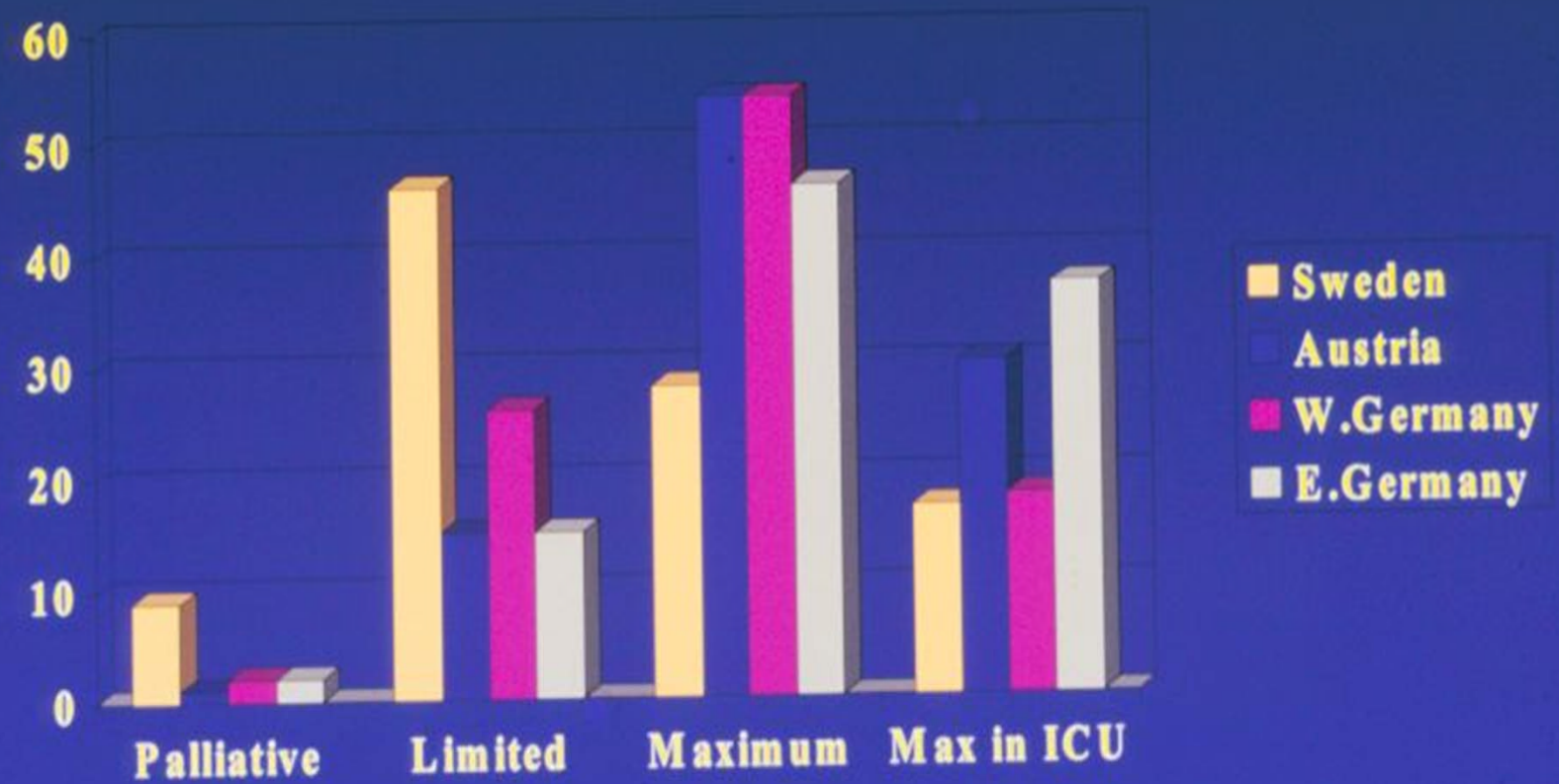
- Palliative, Limited, Surgical or Intensive
- CPR or no CPR?
- Tube or No Tube feeding?


Individual Countries : No Directive
70
60
50
40
30
20
10
0
% of sample
CAN
USA
AUS
SCOT
WALES
SWED
BRAZ
Countries
SUPP
LIM
MAX
MICU

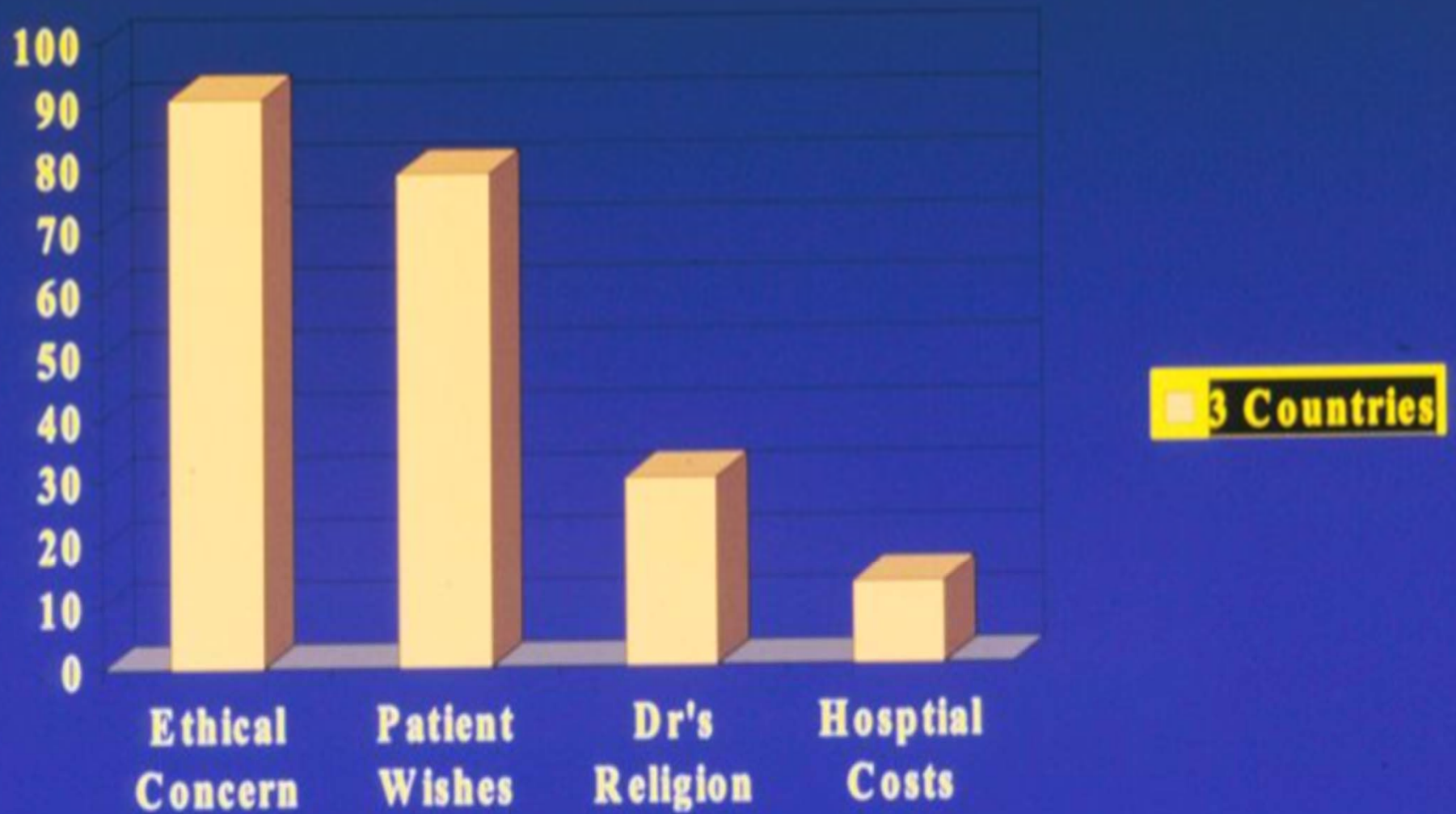

Nurse's Treatment Options : No Directive
60
50
40
30
20
10
0
% of sample
CANADA
SWEDEN
WALES
SCOTLAND
Country
SUPP
LIM
MAX
MICU


Nurse's CPR Options : No Directive
100
80
60
40
20
0
% of sample
CANADA
SWEDEN
WALES
SCOTLAND
Countries
CPR
NO CPR

No-information



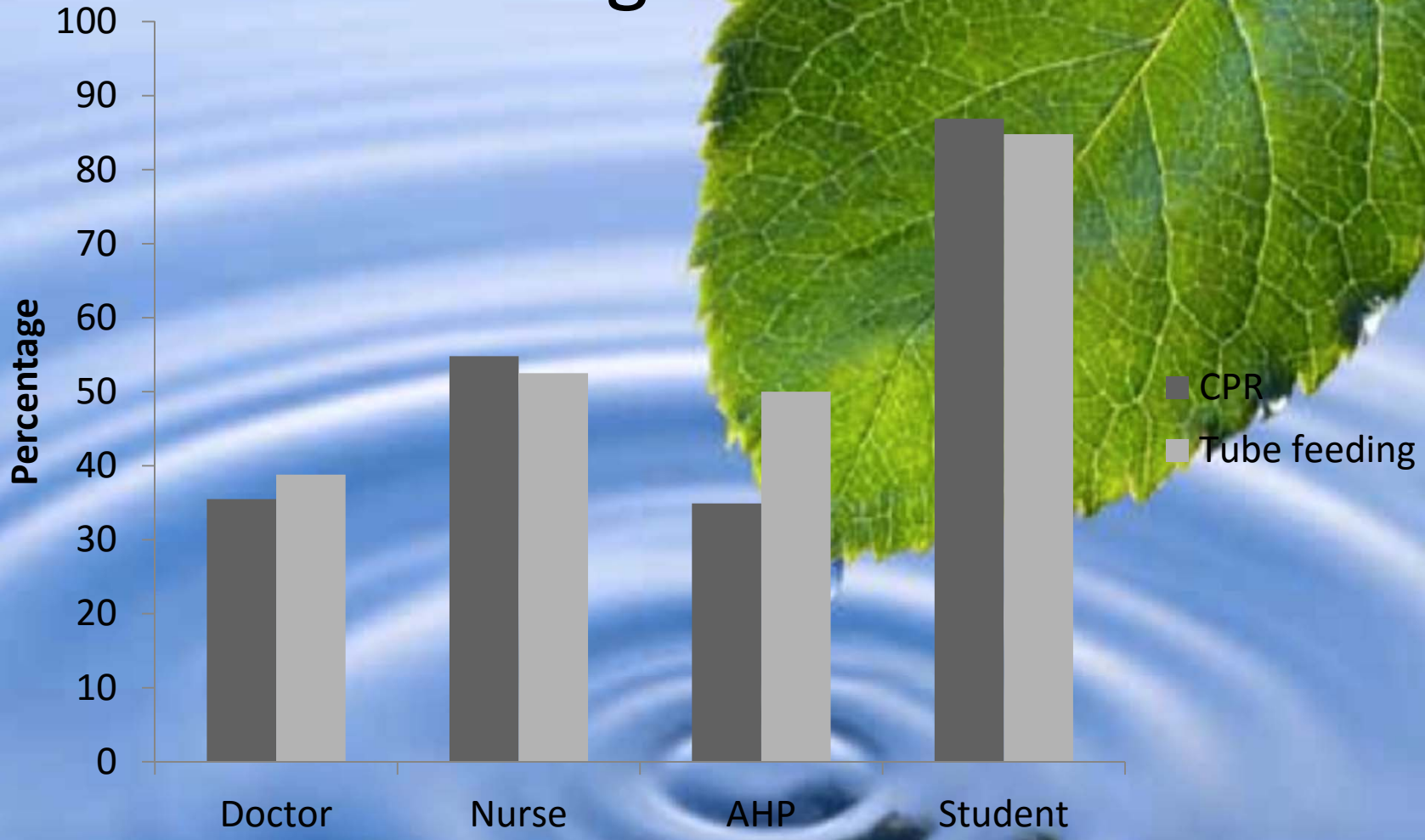
Most Important Factors



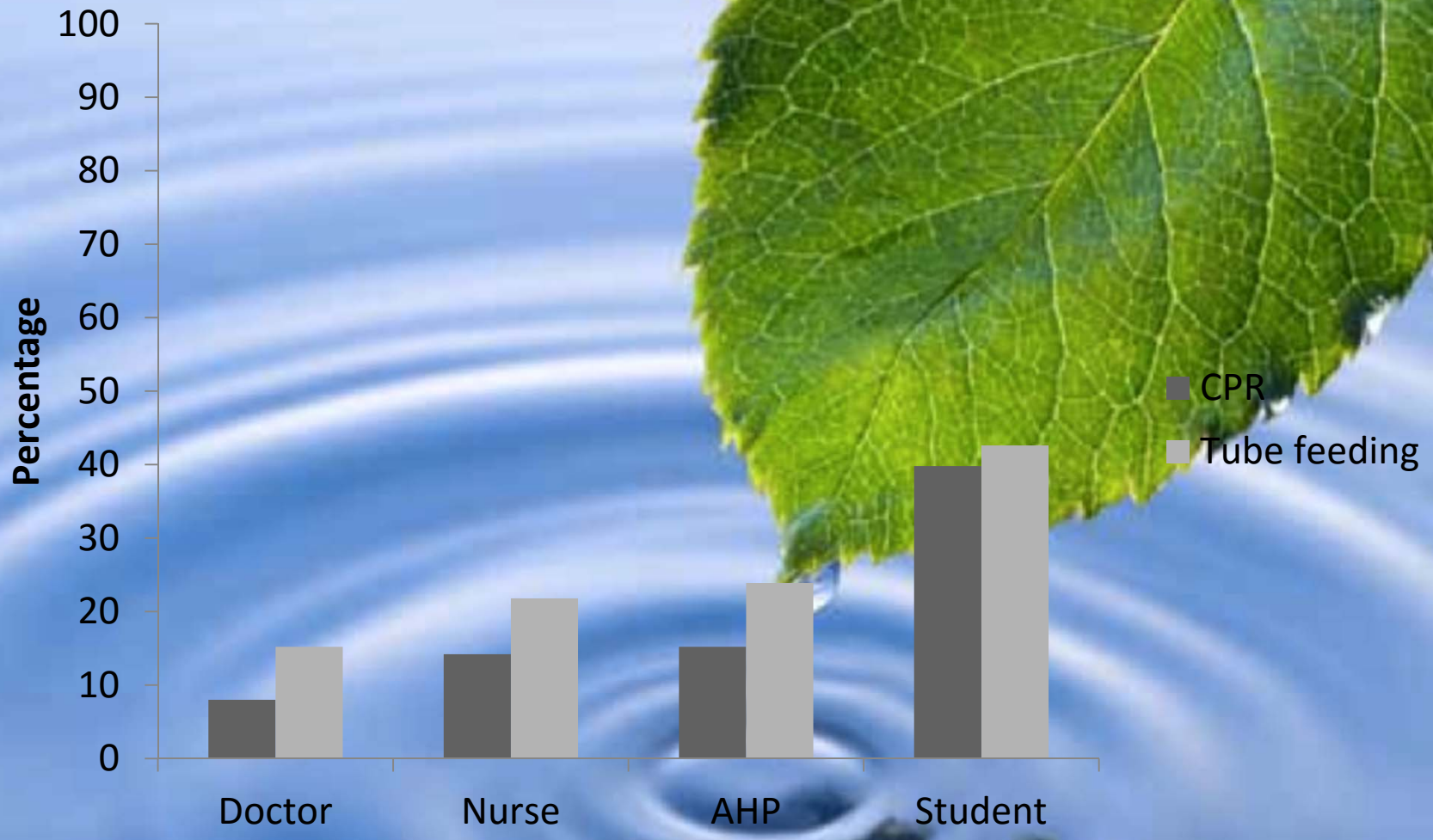
What do we know about Advance Care Directives?

- Number surveyed: **n = 959**
  - Doctors, Nurses, Allied Health Professionals, Medical and Nursing students
- Median age: **33 yrs** (range: 18-82yrs)
- Median age of professionals: **41yrs**
- Gender: **31% male**
- Countries surveyed:
  - Ireland: 757 surveyed
  - UK: 95 surveyed
  - Canada: 107 surveyed (median age 55*, 45% male)

CPR and Tube feeding for case scenario given



CPR and Tube feeding for themselves



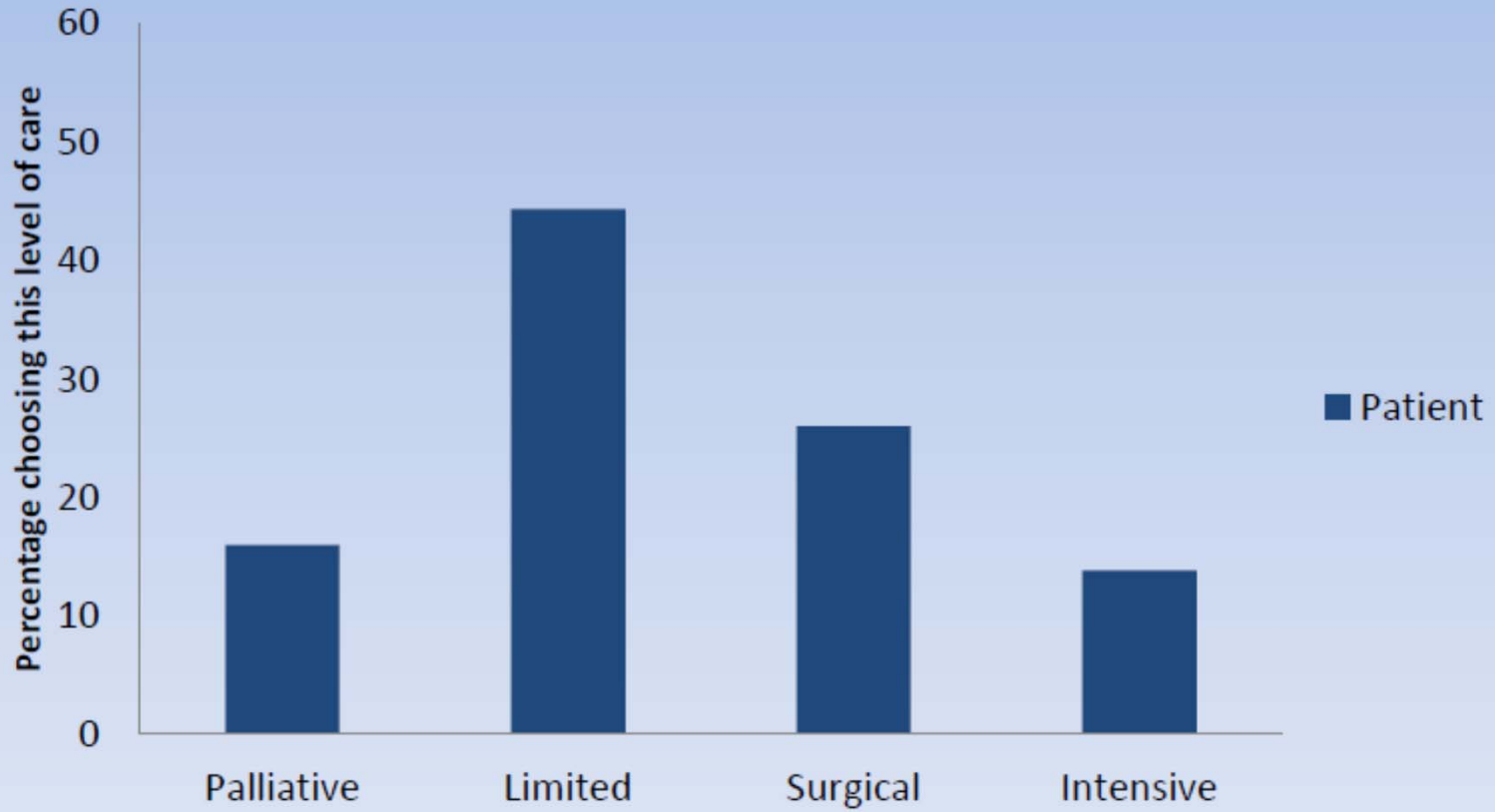
Advance Directives: Nurses' knowledge, attitudes and preferred end-of-life treatment choices in five countries

Coffey A. *et al* (In press)

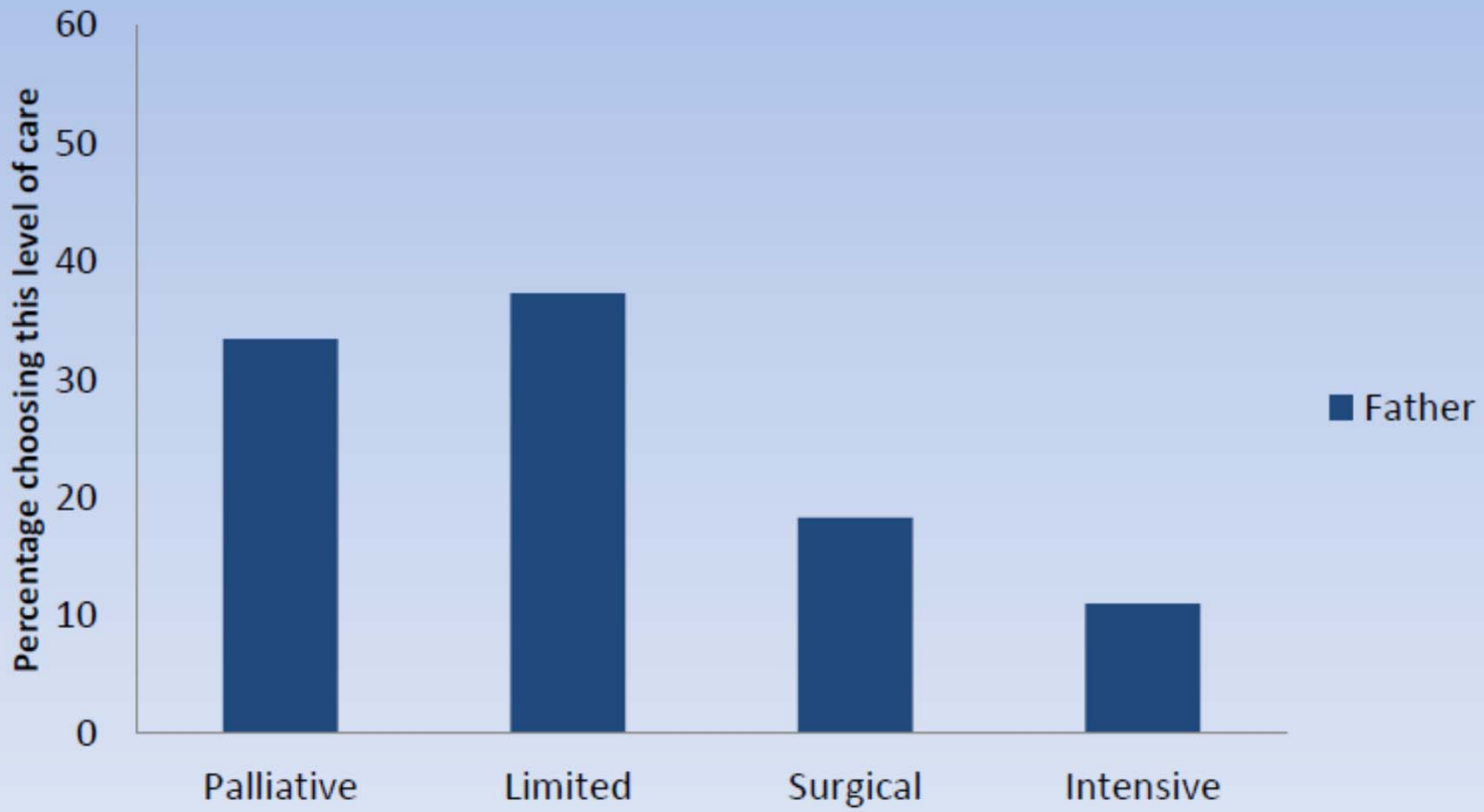
Age, Gender & Discipline of Nurses

	HONG KONG (n=157*)	IRELAND (n=186*)	ISRAEL (n=141*)	ITALY (n=261*)	US (n=344*)
Age					
≤ 35 years	81%	53%	58%	23%	20%
> 35 years	11%	44%	40%	77%	79%
Gender					
Male	17%	6%	13%	30%	4%
Female	81%	89%	87%	70%	96%
Discipline					
General	77%	61%	61%	88%	76%
Specialist	17%	32%	34%	12%	22%
Other	0%	4%	4%	0%	2%

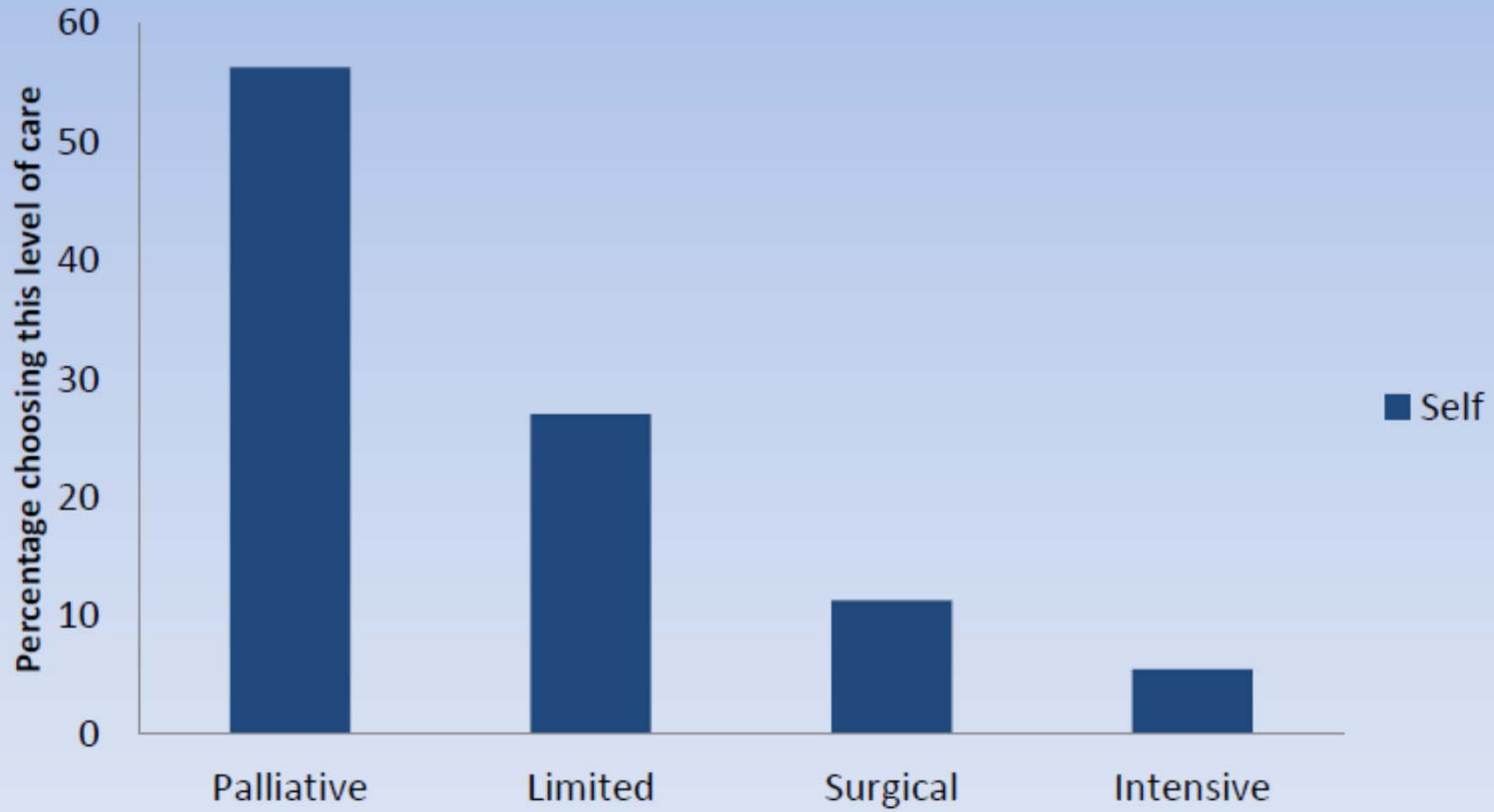
If this was **your patient**



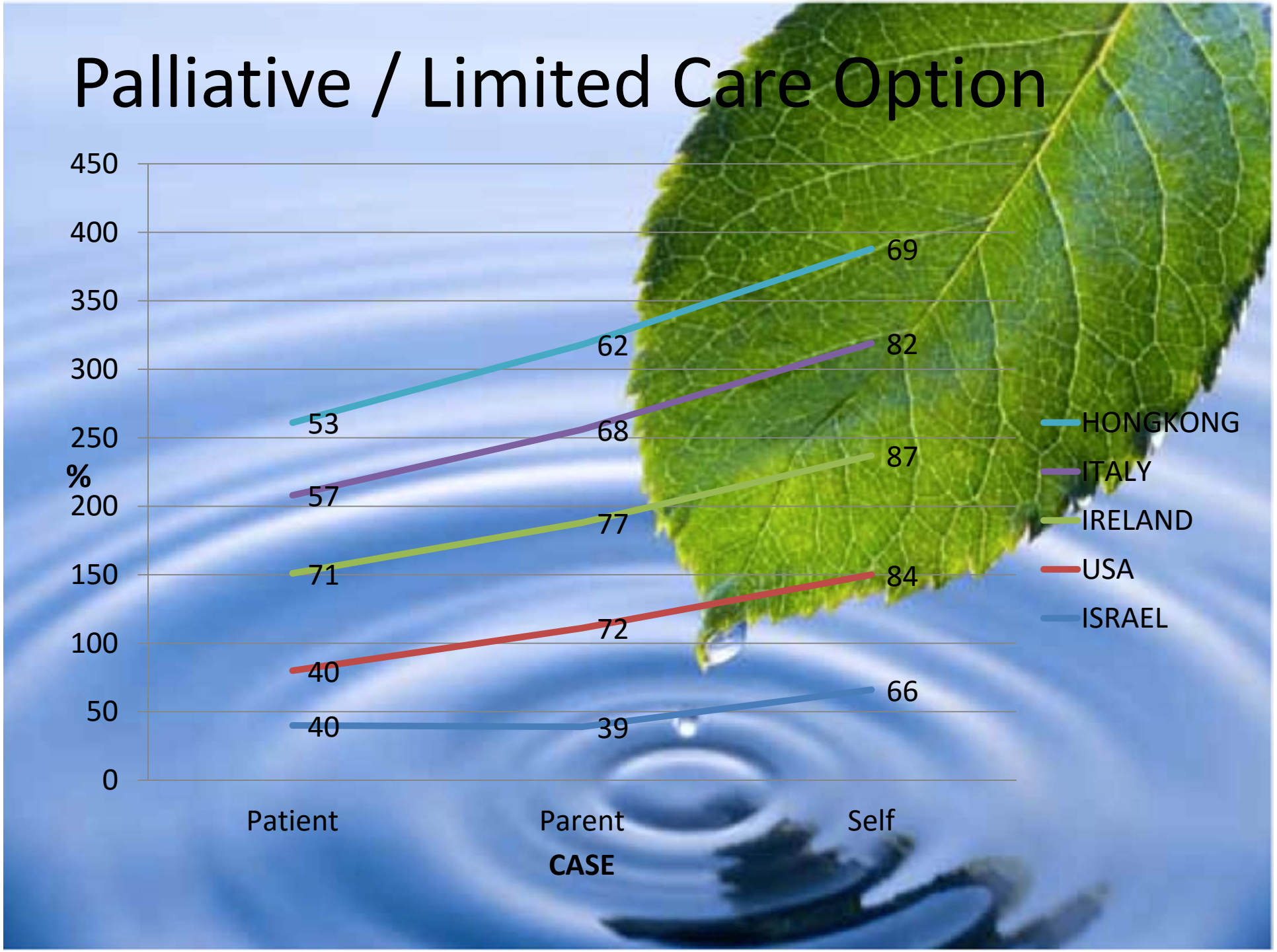
If this was **your Father**



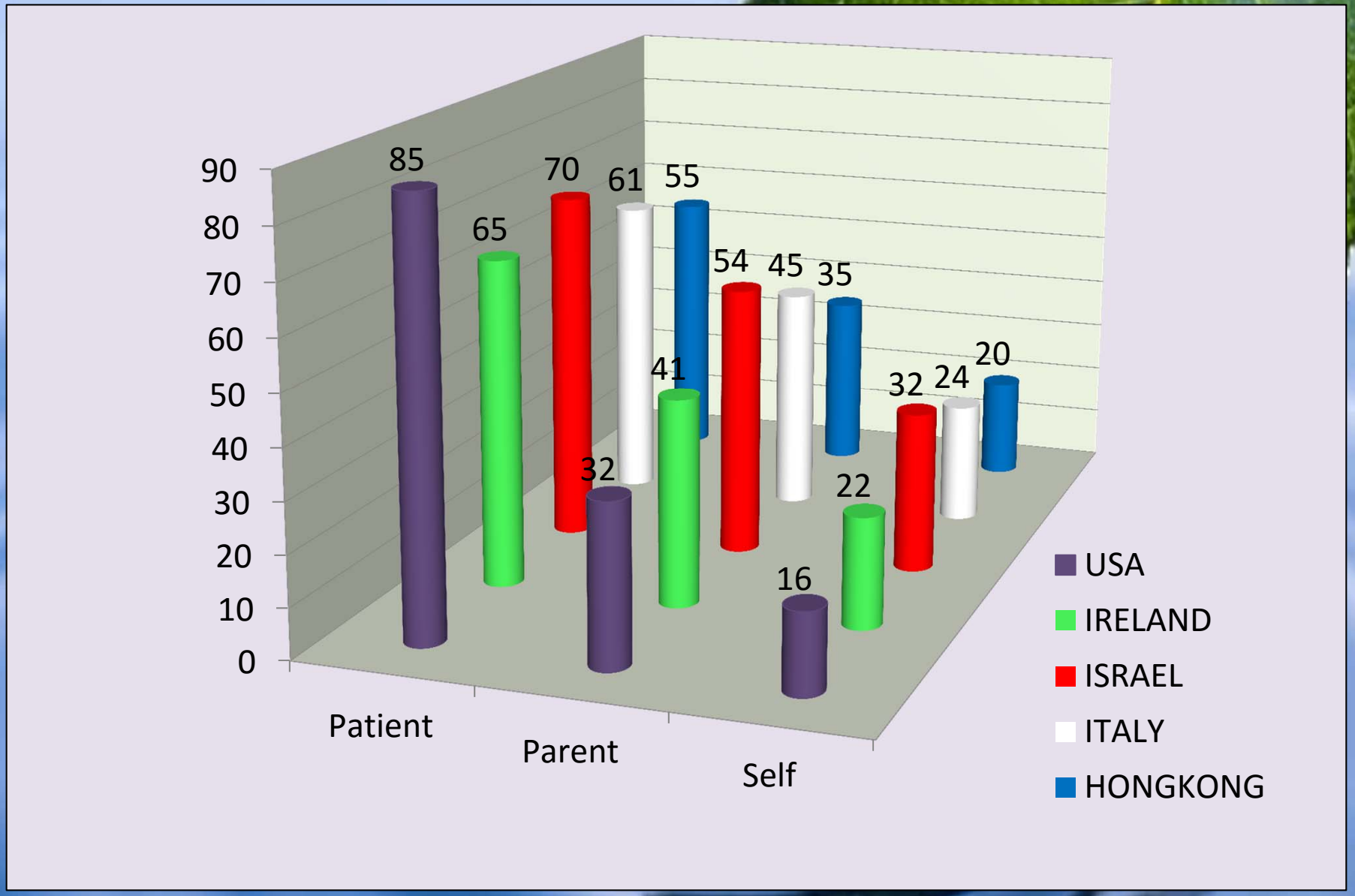
If this was **your self**



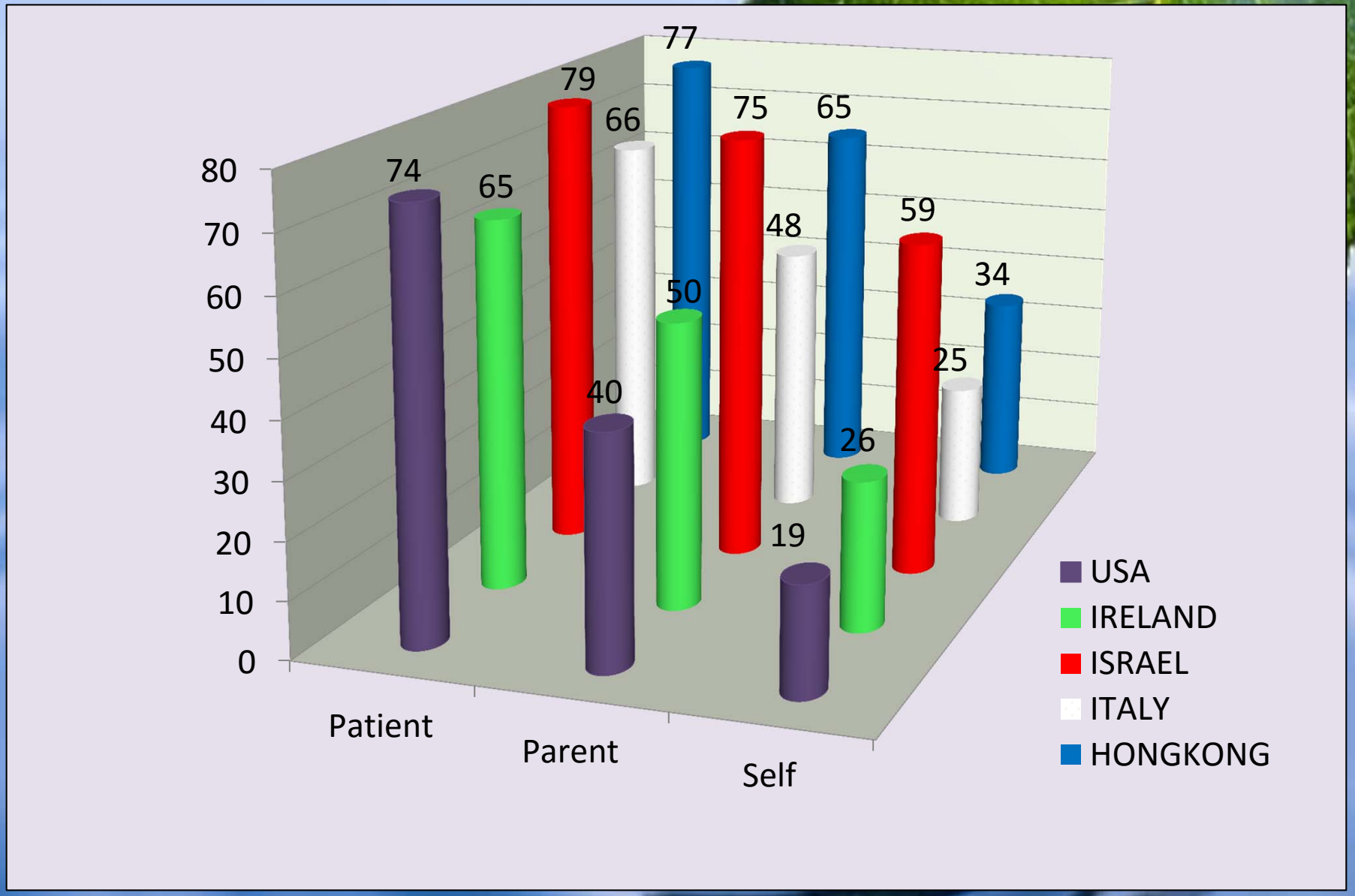
Palliative / Limited Care Option

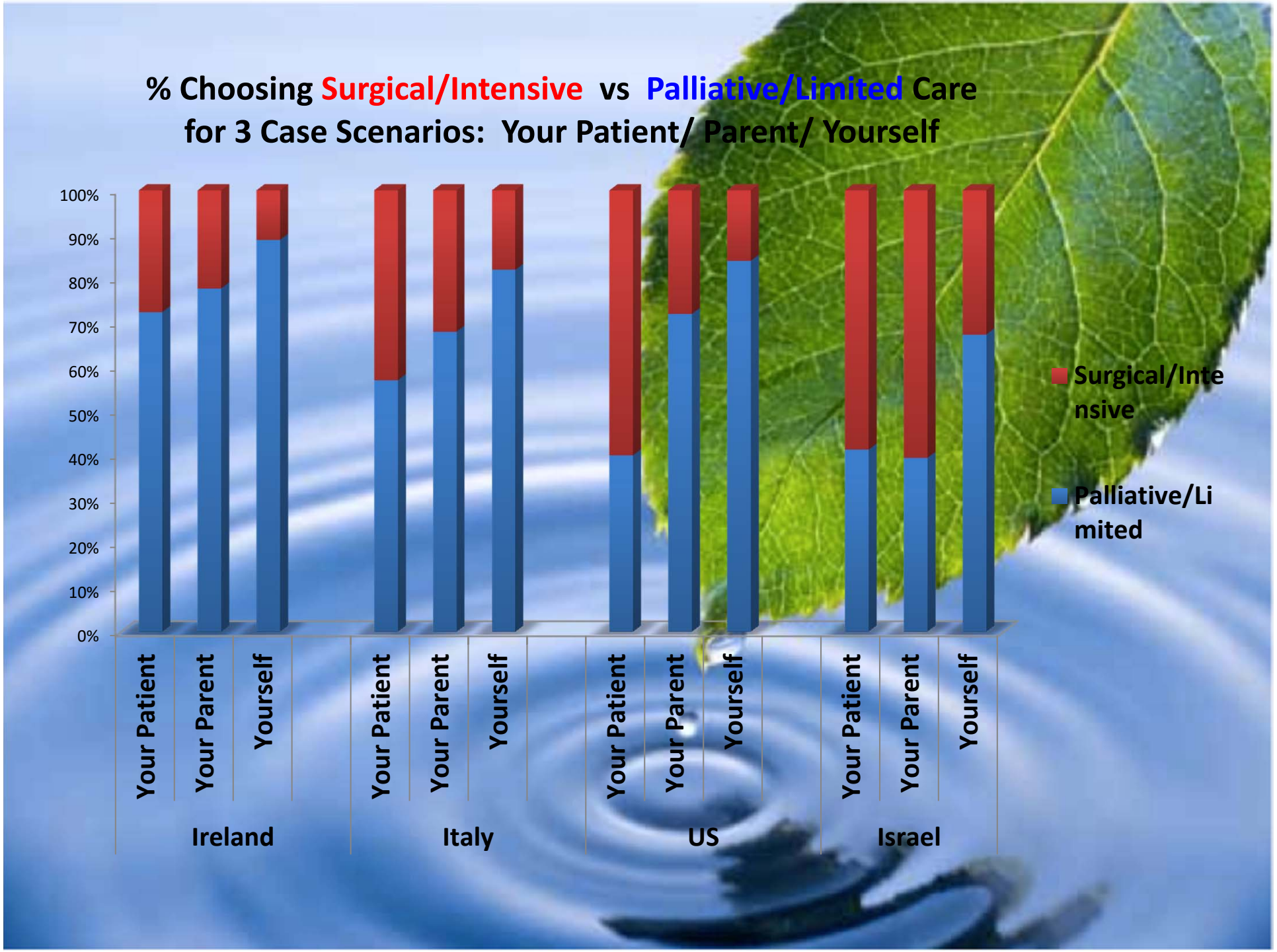


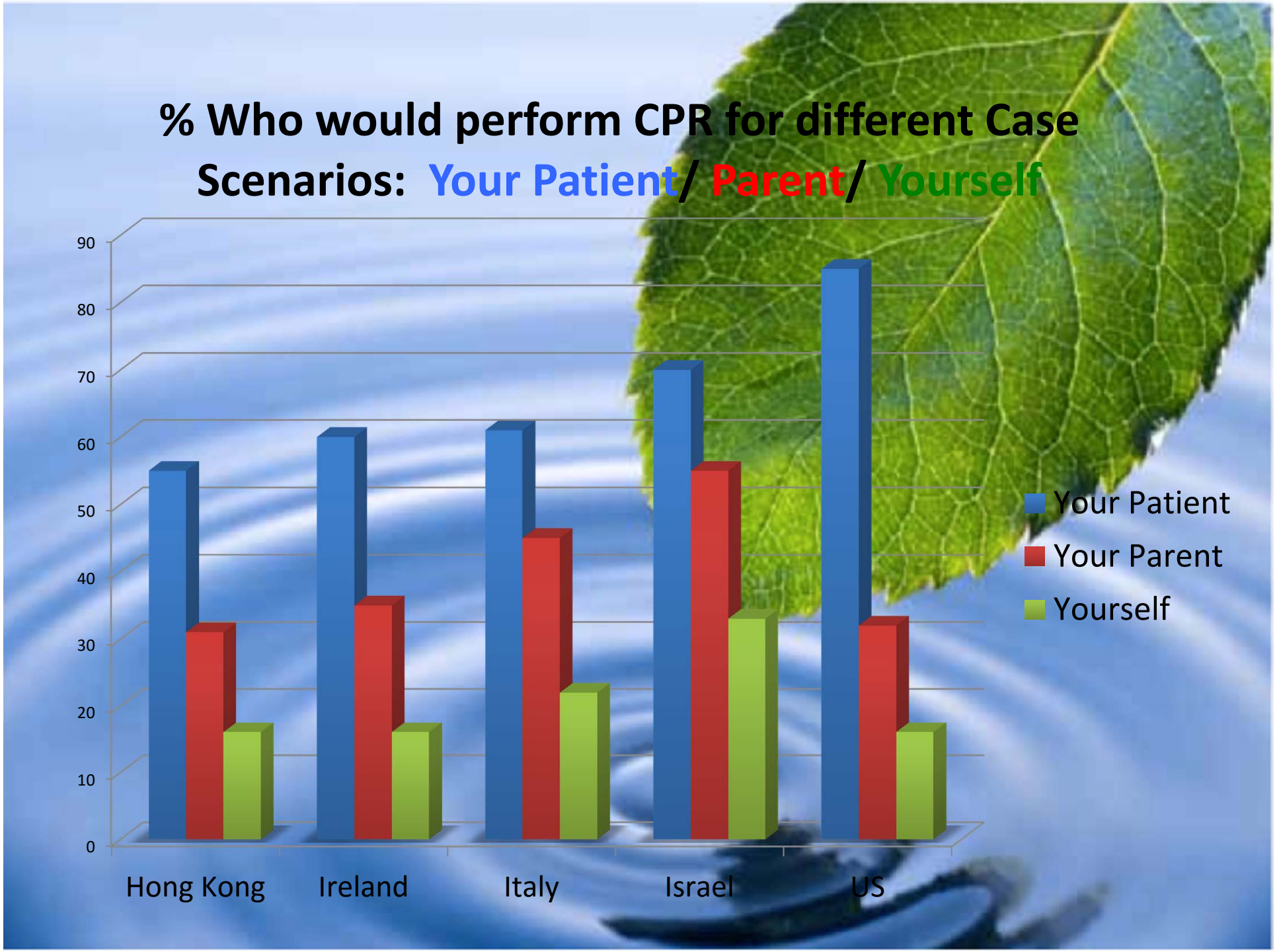
Yes, I would perform CPR

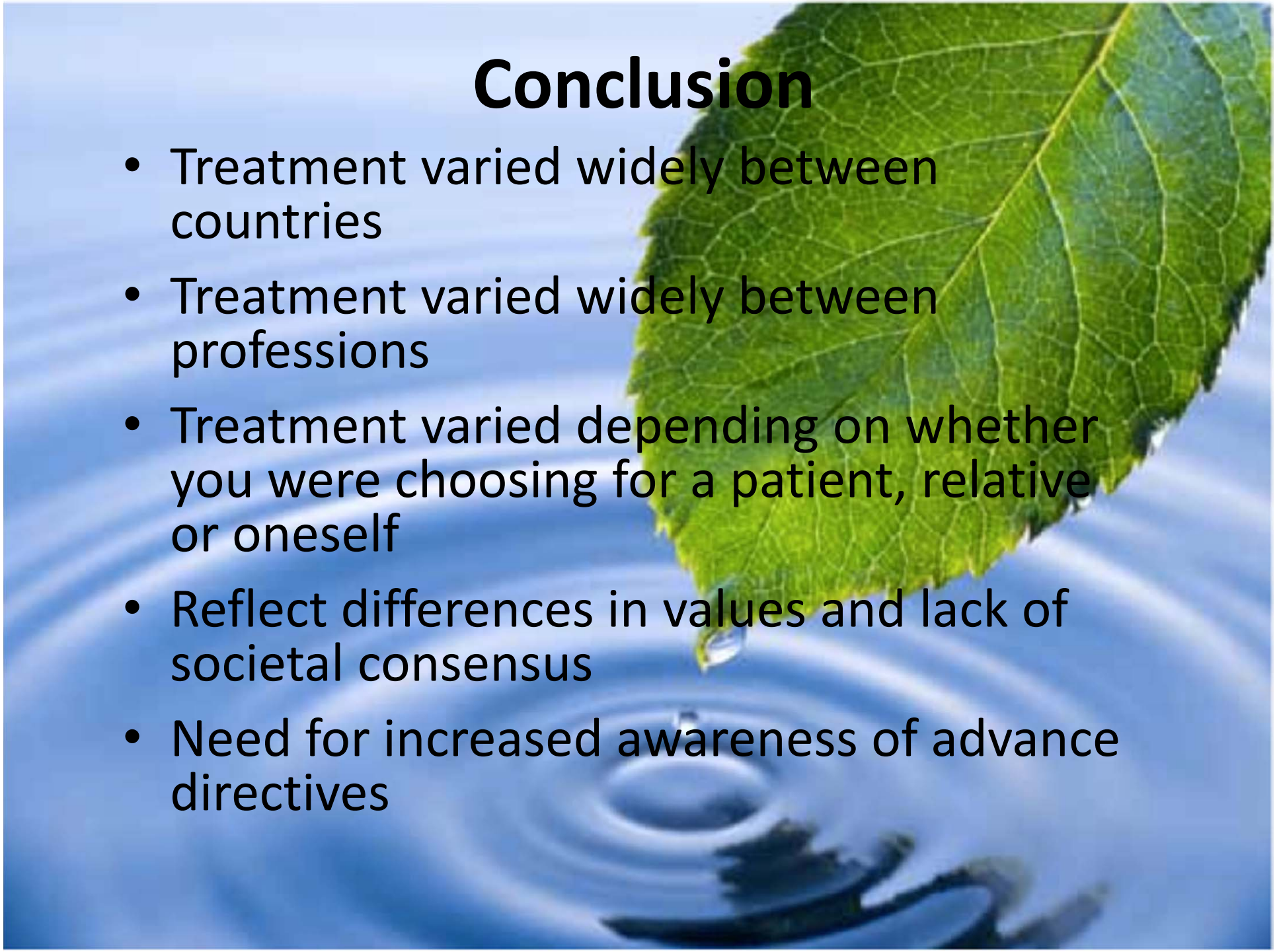


Yes, I would provide artificial feeding




% Choosing Surgical/Intensive vs Palliative/Limited Care
for 3 Case Scenarios: Your Patient/ Parent/ Yourself
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Your Patient
Your Parent
Yourself
Ireland
Italy
US
Israel
Surgical/Intensive
Palliative/Limited


% Who would perform CPR for different Case Scenarios: Your Patient/ Parent/ Yourself
90
80
70
60
50
40
30
20
10
0
Hong Kong
Ireland
Italy
Israel
US
Your Patient
Your Parent
Yourself



Conclusion

- Treatment varied widely between countries
- Treatment varied widely between professions
- Treatment varied depending on whether you were choosing for a patient, relative or oneself
- Reflect differences in values and lack of societal consensus
- Need for increased awareness of advance directives

KEY POINTS

- Interesting differences in preferences among nurses when presented with the case of Mr Murphy as patient, parent and self.
- Irish nurses opted for ‘palliative care’ more often than their counterparts in other countries.
- The ‘Intensive’ treatment option was most popular choice for nurses in the USA and Israel
- Major influences on participant choices were

  Lack of knowledge of patient wishes

  Duty of care.
- Fear of legal action was **not** a major influencing factor, contrary to public perception.


A Randomized controlled
Trial of
A Systematic Application
of An Advance
Directive Program
Molloy DW et al, JAMA 2000; 283:1437-1444

Objectives

To determine the effects of the Let Me Decide program among institutionalized elderly on:

- Patient and family satisfaction with involvement in the level of health care received.
- Health care utilization and cost

Design:

- A randomized controlled trial of three matched pairs of nursing homes in Ontario
- Each pair of homes was matched for size, resident characteristics, mortality and hospitalization rate.

Design:

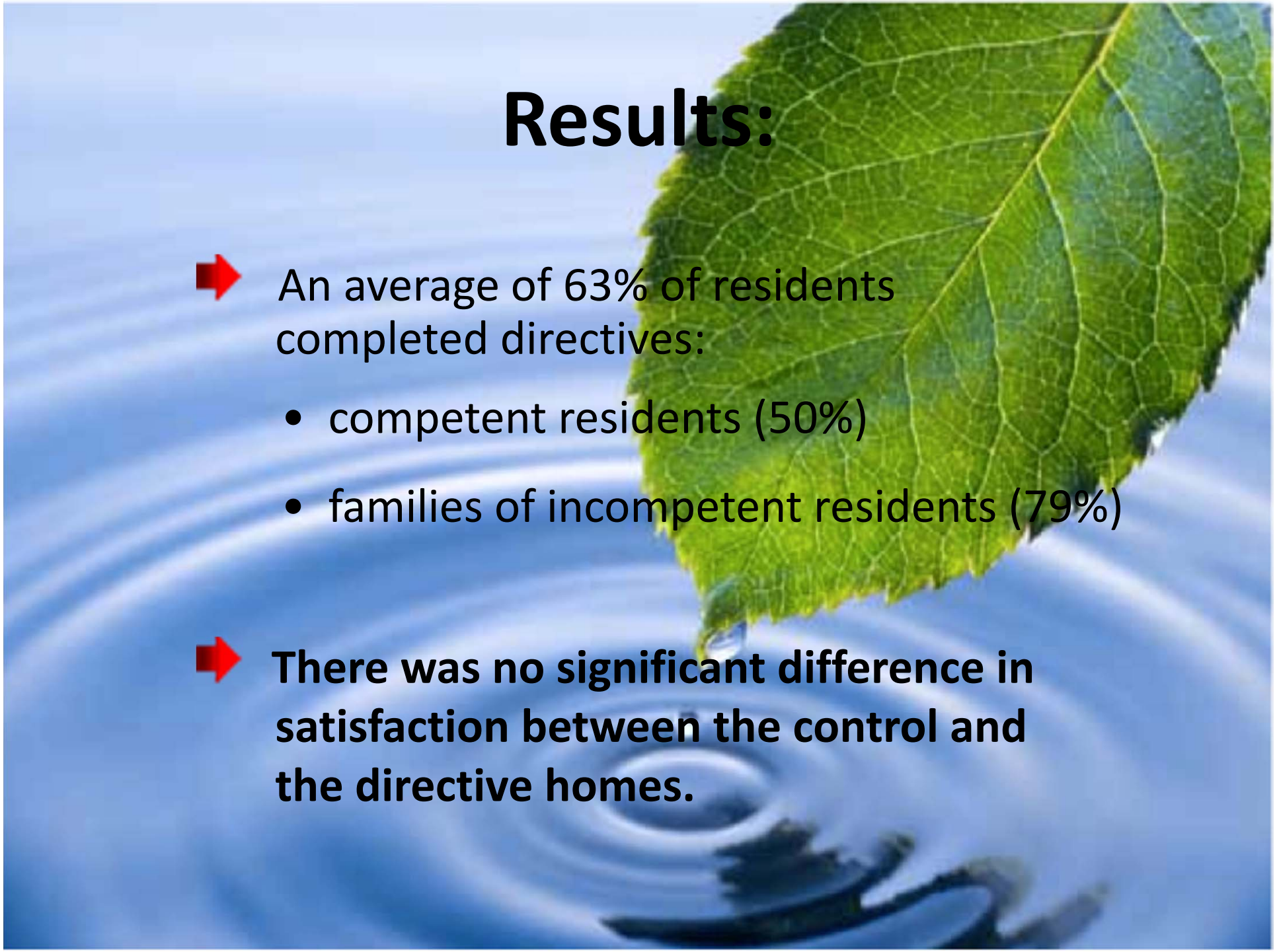
- One in each of the three institutions were randomized to receive the advance directive program and the others to conventional practice

Intervention:

- The staff of each experimental home and associated hospitals received education about advance health care directives
- A trained nurse offered competent residents and families of incompetent residents in the experimental homes an opportunity to complete an advance directive.

Results:

- Residents and families, nursing home and hospital staff were supportive of the use of advance directives
- Hospitalization data show a significant decrease in the number of hospital days in all three experimental homes for the prospective period compared to their matched controls.



Results:

- An average of 63% of residents completed directives:
  - competent residents (50%)
  - families of incompetent residents (79%)
- **There was no significant difference in satisfaction between the control and the directive homes.**

Outcome measures:

- Satisfaction with the level of involvement in decision making process related to their care.
- Health care utilization and cost data was collected retrospectively and prospectively.

Health Care Use

- More admissions to hospital in controls
- 5,400 nights in hospital in controls
- 2,400 nights in LMD homes
- More deaths in controls
- About $2,000 less in LMD group

RCT: Prospective Economic Cost Per Patient

Mean Cost per Resident ($)

Pairs Cost by Category	Experimental Homes	Control Homes	Difference (E-C) in cost per patient ($)	P-value (1)
Combined Homes				
Hospital Costs	1,772 (0)	3,869 (0)	-2,097	.0.003
Drug Costs	1,606 (1,069)	1,370 (901)	236	0.149

(1) P-value based on a one-sample t-test of the difference in means across nursing home pairs

RCT: Prospective Economic Cost Per Patient

Mean Cost per Resident ($)

Pairs Cost by Category	Experimental Homes	Control Homes	Difference (E-C) in cost per patient ($)	P-value (1)
Combined Homes				
LMD	113 (113)	N/A	113	N/A
Implementation Total costs	3,490 (1,499)	5,239 (1,812)	-1,748	0.013

(1) P-value based on a one-sample t-test of the difference in means across nursing home pairs

Deaths and Discharges: Retrospective and Prospective Periods *

	12 Month Retrospective		18 Month Prospective		
Variable	LMD Homes	Control Homes	LMD Homes	Control Homes	P-value
Number of Residents	655	672	527	606	-
Number of deaths (% of total Residents)	135 (21%)	117 (17%)	129 (24%)	167 (28%)	.20
Number of Discharges	13	23	10	16	-

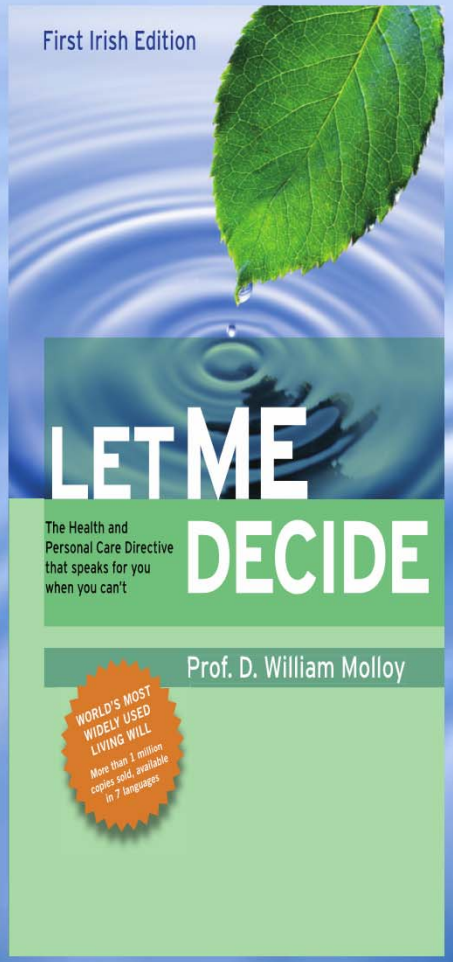
* Difference between Intervention and Control homes for patients participating in the prospective study after adjusting for baseline differences in the retrospective period

Hospitalizations: Retrospective and Prospective Periods *

	12 Month Retrospective		18 Month Prospective		
Variable	LMD Homes	Control Homes	LMD Homes	Control Homes	P-value
Number of Residents	655	672	527	606	-
Hospitalizations (mean Hospitalizations per patient)	197 (0.30)	183 (0.27)	143 (0.27)	290 (0.48)	0.001
Hospitalization Days (mean Hospitalized days per patient)	1728 (2.64)	2024 (3.01)	1378 (2.61)	3551 (5.86)	0.01

* Difference between Intervention and Control homes for patients participating in the prospective study after adjusting for baseline differences in the retrospective period

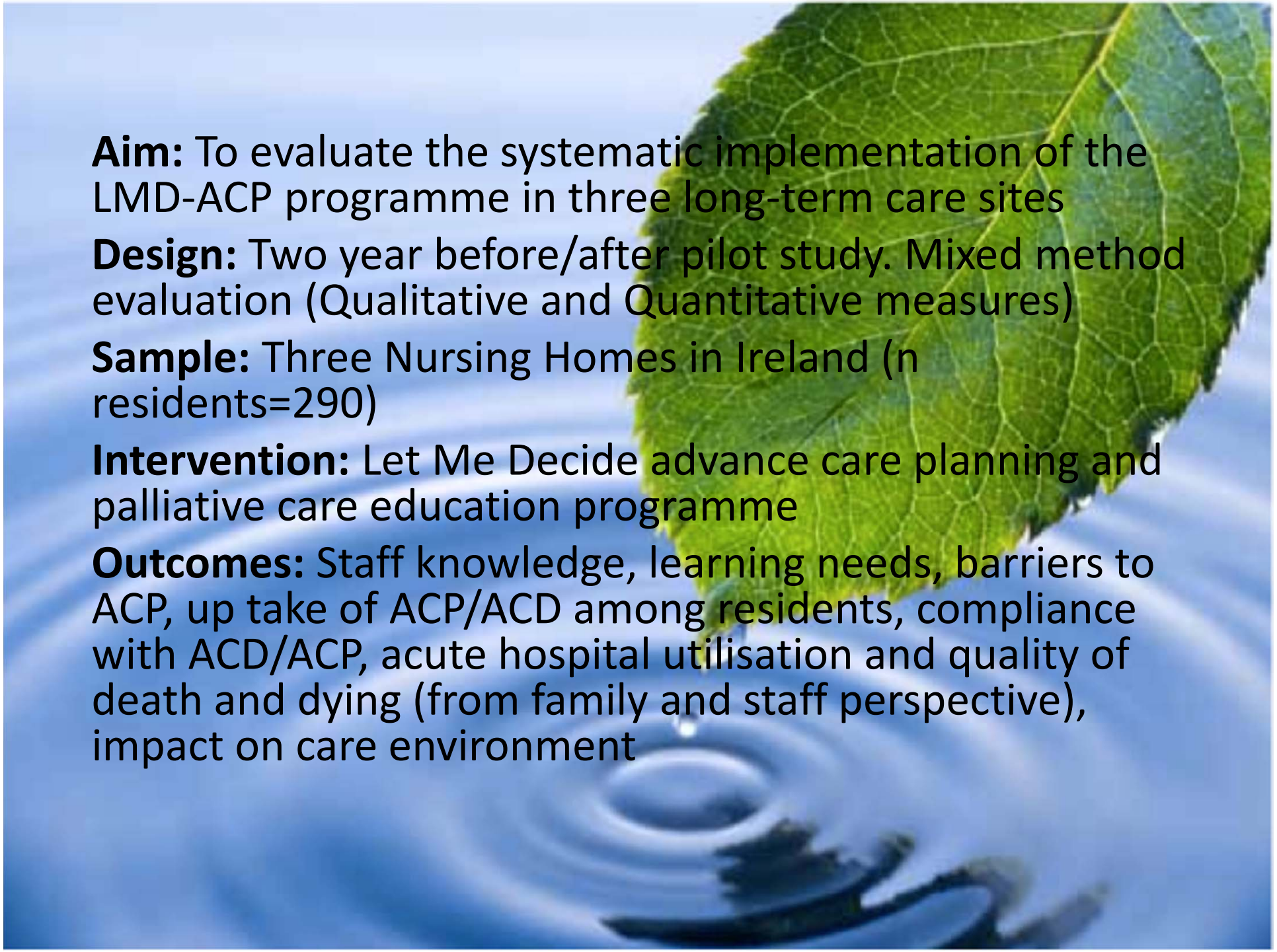
'Let Me Decide' Pilot Study- Ireland



- **Prof Willie Molloy**
- **Dr. Ciara McGlade**
- **Dr. Edel Daly**
- **Dr. Nicola Cornally**

Funded by the Irish Hospice Foundation/Atlantic Philanthropies


‘Let Me Decide’ Programme
The systematic implementation of both an
Advance Care Planning using the
‘Let Me Decide’ Advance Care Directive
and
a General Palliative Care Educational Programme
In long-term care institutions in Ireland


Aim: To evaluate the systematic implementation of the LMD-ACP programme in three long-term care sites
Design: Two year before/after pilot study. Mixed method evaluation (Qualitative and Quantitative measures)
Sample: Three Nursing Homes in Ireland (n residents=290)
Intervention: Let Me Decide advance care planning and palliative care education programme
Outcomes: Staff knowledge, learning needs, barriers to ACP, up take of ACP/ACD among residents, compliance with ACD/ACP, acute hospital utilisation and quality of death and dying (from family and staff perspective), impact on care environment

Why palliative care component?

- Evidence that ACD increase the demand for palliative care
- Evidence of unmet palliative care needs of residents in long-term care
- Evidence of unmet palliative care educational needs of staff in long-term care

Baseline data on Nursing Homes

- **Profile of home** questionnaire
- Baseline residents' demographics
- Staff **Palliative Care educational needs**
- **Attitudes and Barriers** to implementation of Advance Care Planning
- **Chart review** of all deaths in the previous year
- **Quality of Dying and Death (QODD) survey -** to assess the death from the perspective of the relative of deceased resident

Baseline Data

- Suggests high satisfaction with care received
  - Some really good initiatives (easily copied)
- Low level of advance care planning
  - Usually left until person is dying
- Of those who died in LTC
  - 8-11% were transferred in last 3/12,
    - Of these 56% died within 2/52 of return to LTC
- 6-22% died in hospital
  - Local study suggests 14-37% of transfers inappropriate or avoidable
  - Potentially burdensome or unwanted …… plan ahead!


Let Me Decide - ACD training
• Introduction to Advance Care Directives
• Legal Issues
• Ethical Issues
• Practical Issues
• Measuring Capacity
• Completing an ACD

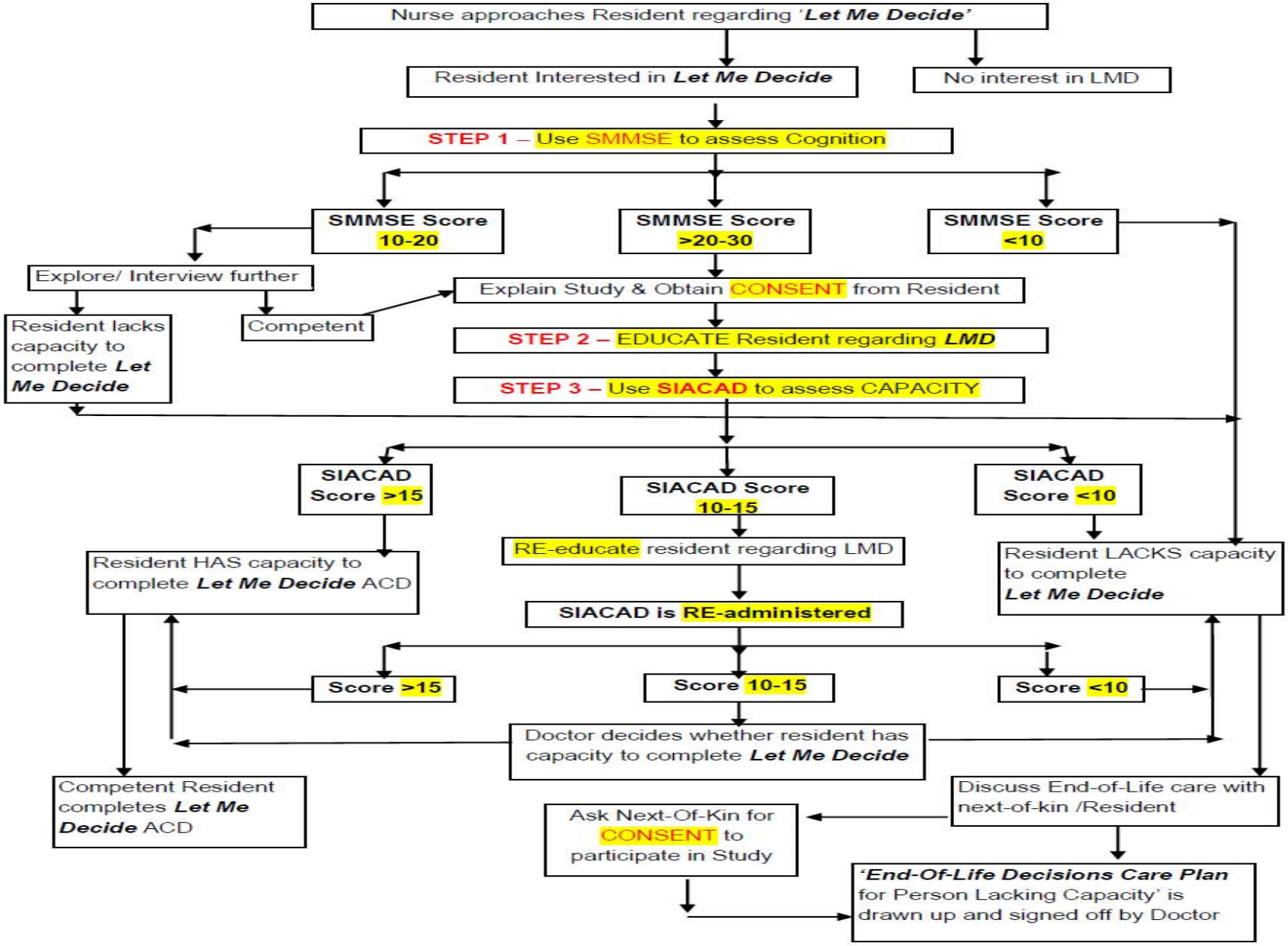
Let Me Decide – Palliative Care Education

- General palliative care education
- Aimed at LTC staff
  - First 3 sessions for nurses & Healthcare assistants
  - Last 3 sessions for nurses
- Five core topics
  - Informed by Staff Learning Needs Questionnaire
    (to build on knowledge & experience of staff)
  - Informed also by the Palliative Care Competency Framework

Let Me Decide-Irishified

- Different legislation here in relation to both ACDs and medical decision-making for people lacking capacity
- Irish edition of '*Let Me Decide*' book (2011)
- LMD form altered for Irish LTC population
- Additional form developed for care planning for residents lacking capacity
- Policy development for institutions

Decision Tree for Implementing *"Let Me Decide"*



Advance care planning and Advance Care Directive up-take

- Following implementation, over 50% of residents had some form of end-of-life care plan in place (advance care directives; advance care plans; or end-of-life care plans for those with diminished capacity).

Nursing Home	ACDs/EOL Care Plans completed (%)
1. 120 Beds	N = 68/120 (57%)
2. 97 Beds	N = 58/97 (60%)
3. 79 Beds	N = 39/79 (50%)

Compliance with wishes

- Despite the high prevalence of cognitive impairment, at least 10% of residents had capacity to complete their own advance care directive.
- Of 70 residents who died during the study period, 84% had an end-of-life care plan in place (12% of these were advance care directives).
- Compliance rates: Of those who died, wishes were fully adhered to in 95% of cases.

Staff survey

Before (n=87)

- 50% had no palliative training
- 40% would feel confident about discussing end of life issues with residents and family
- Palliative care learning need as indicated by over 90%:

Pharmacological Management of Pain and opioids & Understanding the emotional needs of the dying patient

- Barriers to ACP were lack of knowledge among general population and staff and lack of sufficient time to educate resident/family

After (n=93)

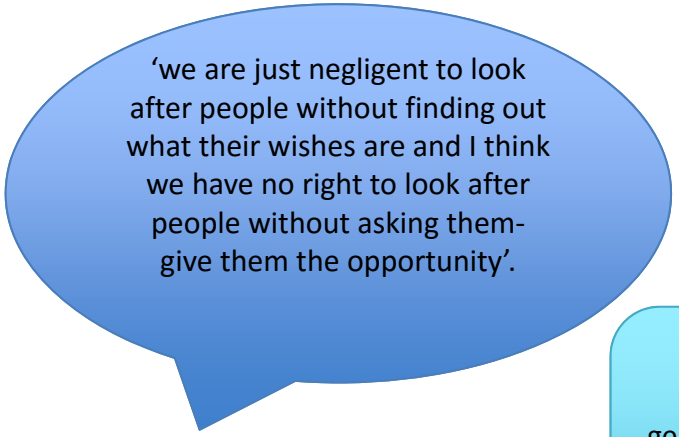
- 82% found our palliative training 'very useful'
- 90% believed that every competent person should become more involved in their decision making
- Pain management remains a 'very important' learning need for over 70%
- 65% felt confident educating and completed ACP/ACDs with residents and family

Qualitative Evaluation of the programme

- Focus groups were conducted with 15 nurse managers/DONs and staff that were involved in implementing the programme.
- Length of focus groups varied between 51mins-72mins

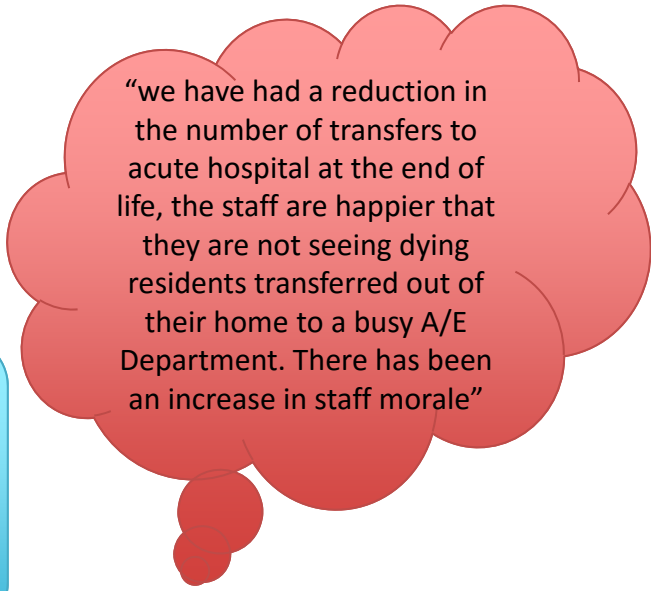
Participants asked to describe ‘Let Me Decide’ in one word

Categories	Subcategories	Codes
Implementing advance care planning	Directing care	Essential for practice
		Care planning for the future
	Implementation of the programme	Fear of unknown
		Support from research team
		User friendly resources
	Emotive process	Emotive process
Benefits	Enhancing communication	Pathway for difficult conversations
		Normalising death
		Building relationships
	Changing care culture	Composed care environment
		Promoting multi-disciplinary awareness
		Enhancing practice and profession
	Avoiding crisis decision making	Reducing emotional distress
		Family preparedness
		Reduce end of life hospital transfer
	Preference-based care	Knowing how to care
		Dignity to decide
Challenges	Establishing capacity	Persons lacking capacity
		Capacity assessment
		Borderline capacity
	Enactment of ACP	Ensuring compliance
		GP involvement
		Legal aspects
	Indecision	Gaining consensus
		Misperceptions of purpose
		Not for everybody
Disadvantages	Resource Intensive	Time and Effort
		Reviewing and updating
Recommendations	Education/training	Train the trainer model
		Blended approach and simulations
	MDT approach	Role of senior nurse and managers
		Getting everyone involved
	Documentation	Capturing conversations
		Sticker alerts on charts
	External support	Link facilitator
		Freely available ACP tool kits
	Introduce concept around admission	Introduce concept around admission

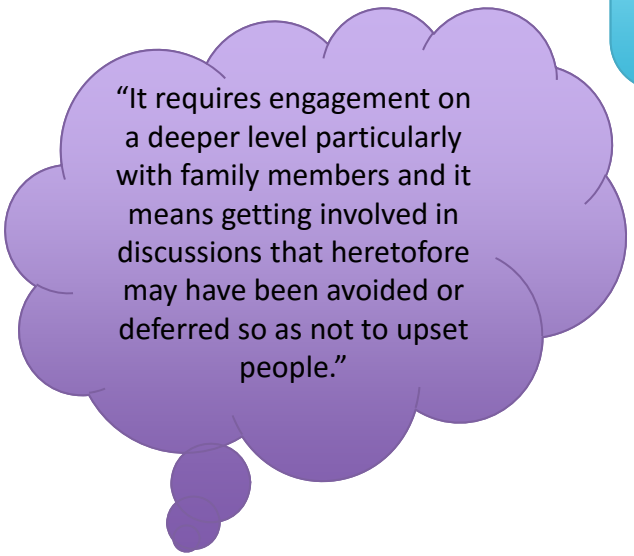


Demonstrating the significance of implementing ACP/ACDs

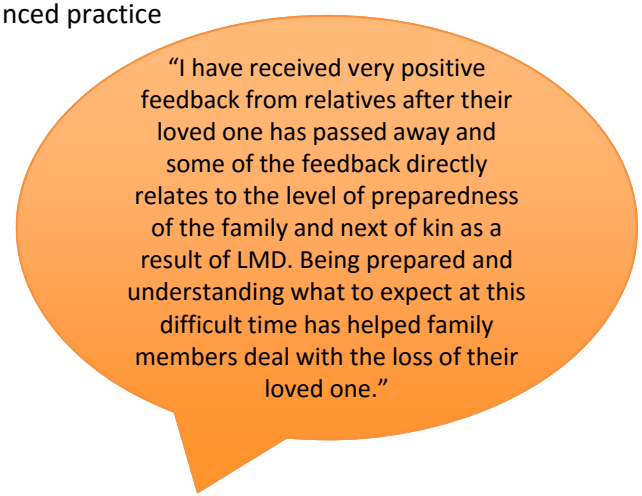
LMD has enhanced practice



These observation by staff have been confirmed by quantitative data



LMD enhanced communication and normalised death – one resident even thanked staff for giving them the **dignity to decide.**



Benefits of the programme have extended to reducing family distress and creating a sense of preparedness at end of life

QODD – Family

- Before (n=104)
- After (n=51)

- Did you get to spend time with relative in the last week of life?

Yes 100 (96%)-Before

Yes 52(98%) – After

- Were you with relative when they died?

Yes 59 (56%) – Before

Yes 39 (76%) – After

- Rate the quality of care provided (v-poor /v-good)

V-good 88 (84.6%)- Before

V-good 43 (81.1%)- After

- Rate Quality of Death (1= terrible 10=almost perfect)

Rate 8-10 inclusive 53(53.5%)- Before

Rate 8-10 inclusive 25(48.1%) – After

Overall there was little change in quality of care provided or quality of death and dying

"….I completed the advance care directive on mums behalf which I am sure helped the doctors and nurses decide on appropriate care"

Staff perception of end of life experience

Symptom	Staff Nurse (n=15)	Healthcare assistant (n=15)	Kappa value (95% CI)	P-value
Pain	28.6%	71.4%	.28 (-.03-.58)	.13
Nausea	10.0%	40.0%	.29 (-.19-.76)	.20
SOB	45.5%	45.5%	.63 (.17-1.00)	.04
Cough	16.7%	33.3%	.57 (.08-1.00	.03
Seizure[1]	-	-	Seizure present constant	-
Hallucination	9.1%	0.0%		-
Constipation	0.0%	16.7%		-
Diarrhoea	40.0%	40.0%	.58 (.07-1.00)	.07
Agitation	33.3%	44.4%	.77 (.35-1.00)	.02
Dry Mouth	35.7%	57.1%	.31 (-.13-.76)	.20
Secretions	50.0%	40.0%	.40 (-.16-.96)	.20
Fatigue	46.2%	53.8%	.54 (.09-.99)	<.05
Decreased Appetite	64.3%	71.4%	.84 (.53-1.00)	.001

Table 1 Inter-rater reliability of the pain and symptom experience at end of life scale

[1] none of the patients experienced seizure symptoms

- Mean scores on the global rating of care scale demonstrated that nurses (M=1.29) and healthcare assistants (M=1.13) perceived the care delivered to be totally acceptable (1=totally acceptable 5= totally unacceptable).
- When asked to rate the quality of dying and death experience from 1-5 (poor - excellent), there was little disparity among raters with mean scores in excess of 4.53.

Challenges to Implementation

RESULTS

Challenges and barriers to implementation

Key challenges identified during the implementation process are outlined in Box 1:

Box 1 Key challenges identified in implementing advance care planning

- Difficulties for management in releasing staff for training
- Reluctance of staff to take ownership of the ACP process, seeing it as a role for management
- Lack of staff confidence and experience with ACP and ACDs
- Lack of adequate time to deliver ACP to residents and their families
- Difficulties educating residents with cognitive impairment
- Failure of other healthcare professionals to recognise completed ACP forms.

Informal Feedback

Recently, an intensive care specialist offered us her views on the usefulness of introducing ACP to LTC residents:

"As clinicians working in intensive care, we all too often see the result of the lack of clear directives in nursing home patients, whereby wholly inappropriate treatments - ventilation, dialysis, surgery are undertaken on people with no hope of return to even the baseline function they had before the acute illness. We often spend days talking to families and primary care physicians, to negotiate some kind of death with dignity in these circumstances, and withdrawal of invasive and futile therapies. In fact, a large part of our job is to manage dying and the expectations of families and doctors.

"The sensitive and supportive way you guided us through the Advance Care Directive decision-making process is greatly appreciated by all of us and by mother in particular (spouse of resident). Although my mother found some of the conversations difficult, she accepts it had to be done and that it was a good idea to get something in writing signed off".

Just to say thanks for including us in the let me decide project. We recently had a young man admitted who had 4 cardiac arrests and subsequently suffered brain damage. We did his end of life care plan on admission. He deteriorated rapidly one day and thankfully had a dignified and peaceful death. His family were relieved, even though initially they were a bit taken aback at the prospect of him not being resuscitated – considering he had survived 4 previous attempts!

Its certainly the way to go and has been a tremendous help to us in caring for people at the end of their life.

Thanks again

Future Plans

HRB application €350,000

- Large randomised pilot (parallel-arm cluster RCT with subsequent cross-over whereby the control converts to active)
- 6 homes recruited and matched based on clinical/demographic profile and randomly assigned to groups

Collaboration

- Working with EU partners in different settings e.g. Portugal, Spain.
- Starting in the community now.

Innovative aspects from pilot

- Development and testing of education materials- including simulation model
- Educating broader healthcare team (including topics on medication management and prescribing at end of life)
- Testing new staff measurement tool (SPELE)
- Development and testing of patient centred measurement

(Patient Experience of Pain and Symptoms at End of Life (PEPSEL))- PhD student employed 2015-2018

- Health economics work package

Educational Materials

- Let Me Decide Book
- Training program on line for LMD and palliative care with CME credits and certification.
- Let Me Decide translations
- Let Me Pass Gently: Guide to LMD
- Workshop
- Lecture materials
- Instruments to measure quality of care in patients with cognitive impairment.

Key publications for Q1 2015

- Cornally N, Weathers E, Coffey A, Daly E, McGlade, C, Molloy, D.W. Measuring staff perception of end-of-life experience (SPELE) of older adults in long term care. Accepted; Applied Nursing Research
- Daly E, Cornally N, Coffey A, McCarthy, J, Weathers E, Molloy, D.W. Challenges in implementing Advance Care Planning in long-term care. Accepted; Nursing Ethics
- Weathers E, Cornally N, Coffey A, Daly E, O'Caoimh R, Molloy, D.W. Planning for end-of-life: a systematic review of randomised controlled trials conducted in older adults, Submitted to The Gerontologist 2015, under review.
- Cornally N, McGlade C, Weathers E, Daly E, Fitzgerald C, O'Caoimh R, Coffey A, Molloy DW. Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: A user's perspective. Submitted to BMC Palliative Care 2015, under review.

Thank you