

# Advance Care Planning in the face of changing preferences of patients

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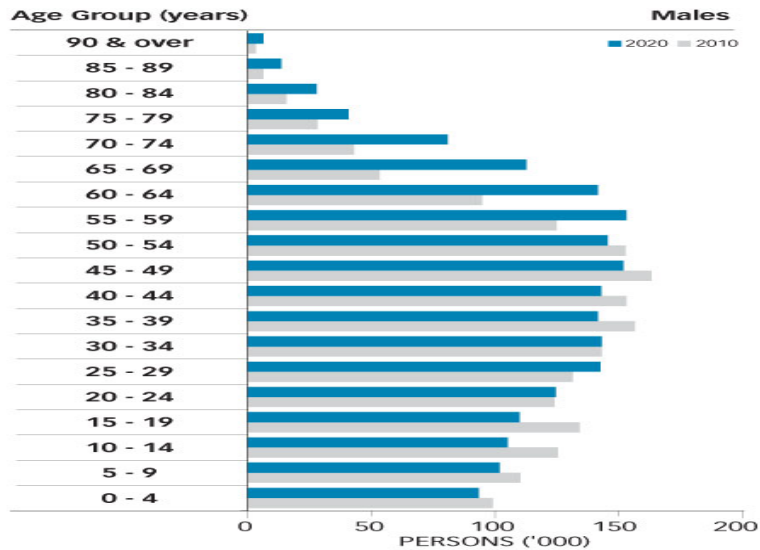
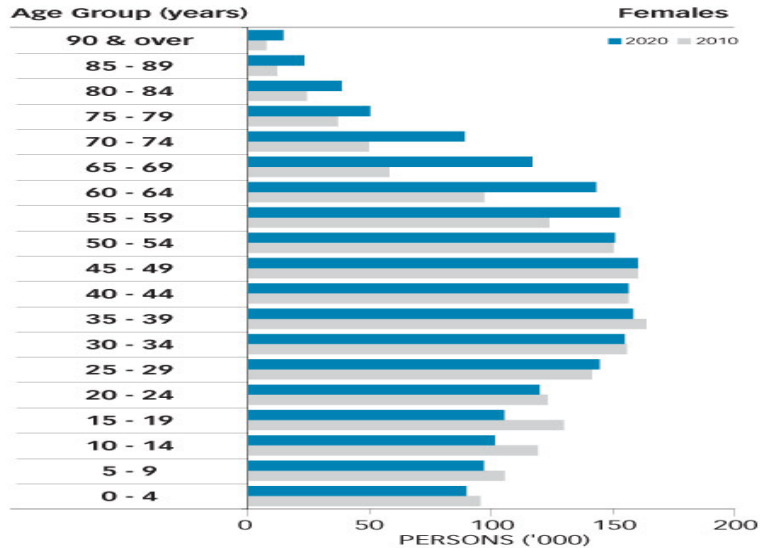




Median age  
(2010) **37.4**

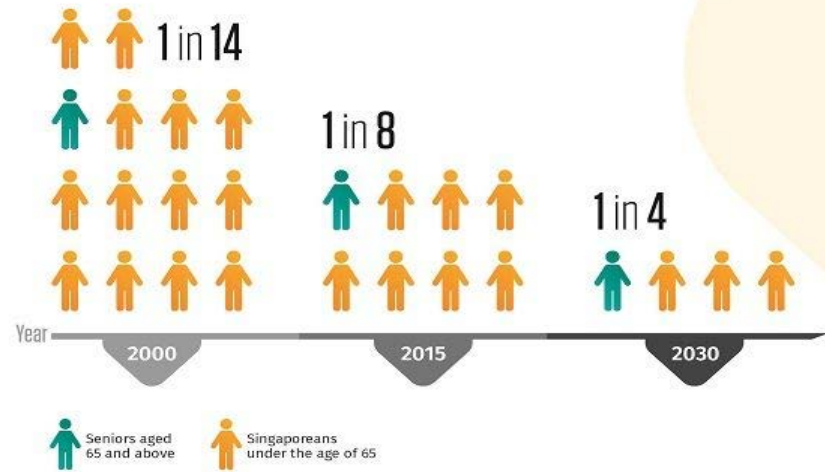
Median age  
(2020) **41.5**

### AGE PYRAMID OF RESIDENT POPULATION

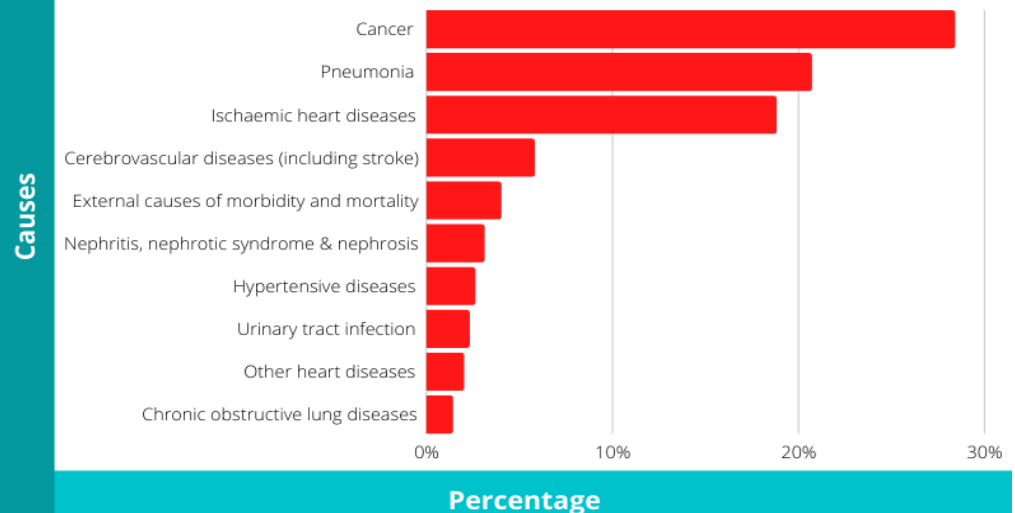


Source: Census of Population 2020  
BT graphics

## OUR POPULATION IS AGEING RAPIDLY



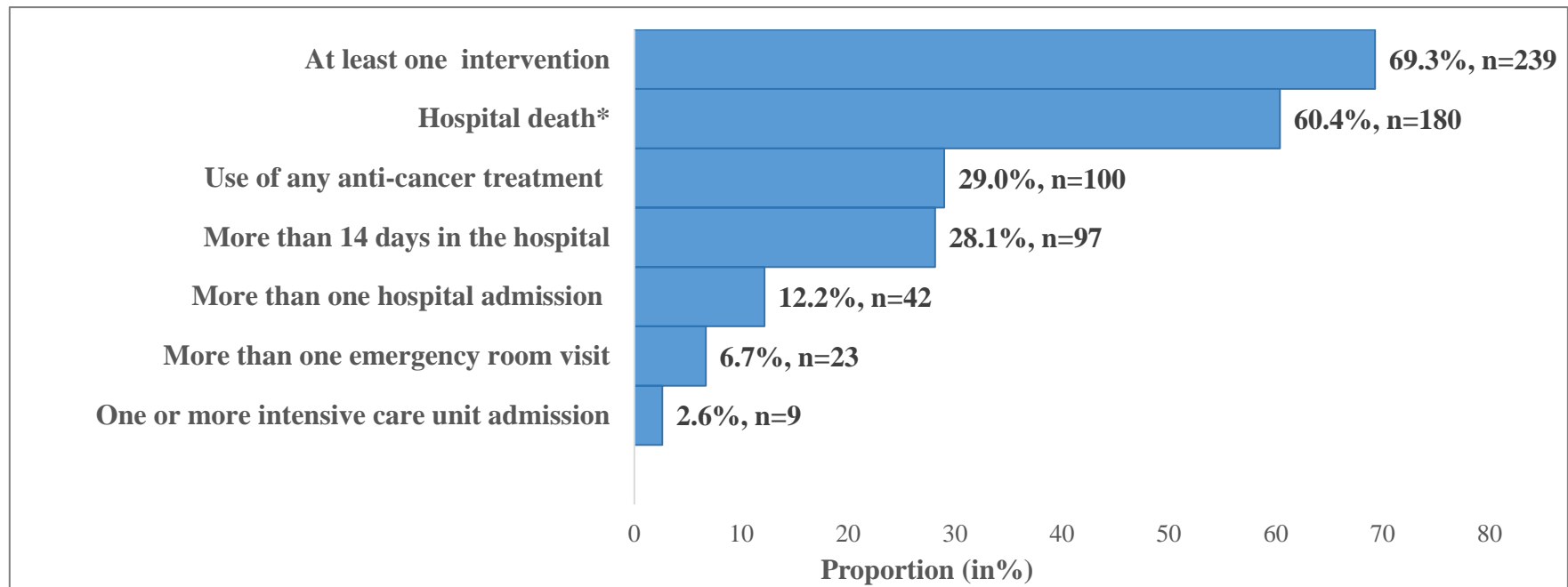
## Cancer is the top cause of death at 28.4%



**WHAT CARE DO PATIENTS  
RECEIVE AT THE END OF LIFE  
(EOL)?**

# EOL care for advanced cancer patients

- In the last month of life, 69% receive care that is categorized as aggressive.

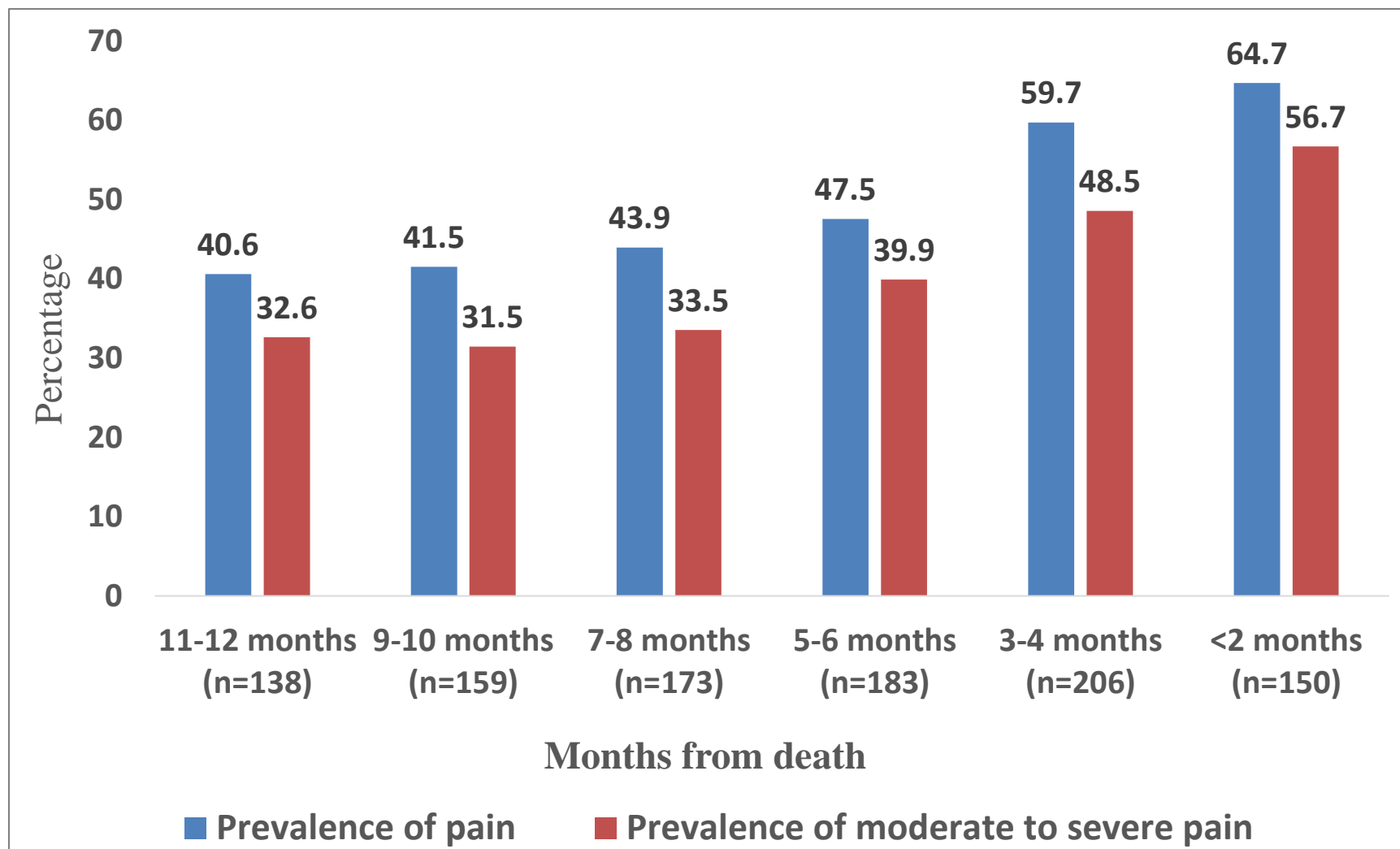




# Effect of aggressive EOL care on bereaved caregivers

- Bereaved caregivers of patients who were treated aggressively:
  - Were more likely to feel that patient's death was prolonged
  - Felt less prepared for patient's death
  - Experienced worse mood following patient's death

# Prevalence of pain at the EOL



Reference: Unpublished data from 345 decedents from COMPASS study



**IS IT WHAT PATIENTS  
WANT?**

# Good EOL care: Perspectives of general public

- Focus groups with older Singaporeans regarding what EOL care they want:
  - Not inappropriately prolong life
  - Be without pain (proxy of quality of life)
  - Not be a burden for family members/ friends
  - Die at a place of choice
  - Receive quality health care (be treated with dignity, receive coordinated care, have a doctor I can talk to,..)?
  - Avoid expensive care

# **We conducted a Discrete Choice Experiment with patients with advanced cancer and their caregivers**

- DCE's tell us what people prioritize if they have to make choices and how much they would pay for their preferred choice

Malhotra C et al. Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment. Palliative Medicine. 2015; 29(9): 842-850.

# Which scenario would you choose?

	Scenario A	Scenario B
Severity of pain from diagnosis until death	Moderate pain	No pain
Amount of care required from family / friends	24 hrs/week	10 hrs/week
Expected length of survival	10 months	4 months
Quality of health care experience	Poor	Very Good
Expected cost of treatment from diagnosis until death	S\$ 20,000	S\$ 4,000
Source of payment	Own Medisave account	Family member's out-of-pocket
Place of death	Home	Institution such as hospital, hospice, or nursing home
Which scenario do you prefer?	<input type="checkbox"/>	<input type="checkbox"/>

# How about for this one?

	Scenario A	Scenario B
Severity of pain from diagnosis until death	Mild pain	Moderate pain
Amount of care required from family / friends	40 hrs/week	10 hrs/week
Expected length of survival	4 month	6 months
Quality of health care experience	Poor	Fair
Expected cost of treatment from diagnosis until death	S\$ 10,000	S\$ 10,000
Source of payment	Own out-of-pocket	Family member's out-of-pocket
Place of death	Home	Institution such as hospital, hospice, or nursing home
Which scenario do you prefer?	<input type="checkbox"/>	<input type="checkbox"/>

# Willingness to pay estimates of patients and caregivers (n=211)

Attribute	Level transition	WTP	
		Patients	Caregivers
Survival	4 months >> 16 months	18,570	61,370 <sup>a</sup>
Place of death	Institution >> Home	31,250	67,720 <sup>a</sup>
Pain	Severe pain >> No pain	22,200	76,050 <sup>a</sup>
Amount of care from family members/friends	40 hrs/wk >> 10 hrs/wk	4,050	- 5,140
Quality of health care	Poor >> Very good	16,190	44,050 <sup>a</sup>

- For patients, extending life is not their top priority
- Caregivers have higher WTPs for all factors other than amount of care

Note: <sup>a</sup> indicates that estimates are significantly different from those for patients at the 95% level.

**HOW CAN WE MEET PATIENT  
PREFERENCES FOR CARE?**



# Advance care planning (ACP): Does it have the potential?

- ACP is one of the most discussed interventions to promote EOL conversations.
- It enables understanding and sharing of values, goals, and preferences regarding future medical care.

## Getting Started!

Just 4 simple steps :

1 Think about it

2 Discuss with your loved ones

3 Put your wishes in a Plan

4 Review your preferences

What does Living Well mean to you?  
What gives your life purpose?  
What makes each day meaningful?

For more information about Advance Care Planning, visit [www.livingmatters.sg](http://www.livingmatters.sg)



# Advance care planning

- Singapore model is based on the 'Respecting choices model'.
  - Has the potential
  - But is it effective in meeting patient preferences for care?
- No data available in the Asian context, including Singapore

**We conducted a randomized  
controlled trial to assess the  
effectiveness of ACP in heart  
failure patients**

Malhotra C et al. Impact of advance care planning on end-of-life care for patients with heart failure: Results from a randomized controlled trial. Journal of Cardiac Failure 2020 Jul;26(7):594-598

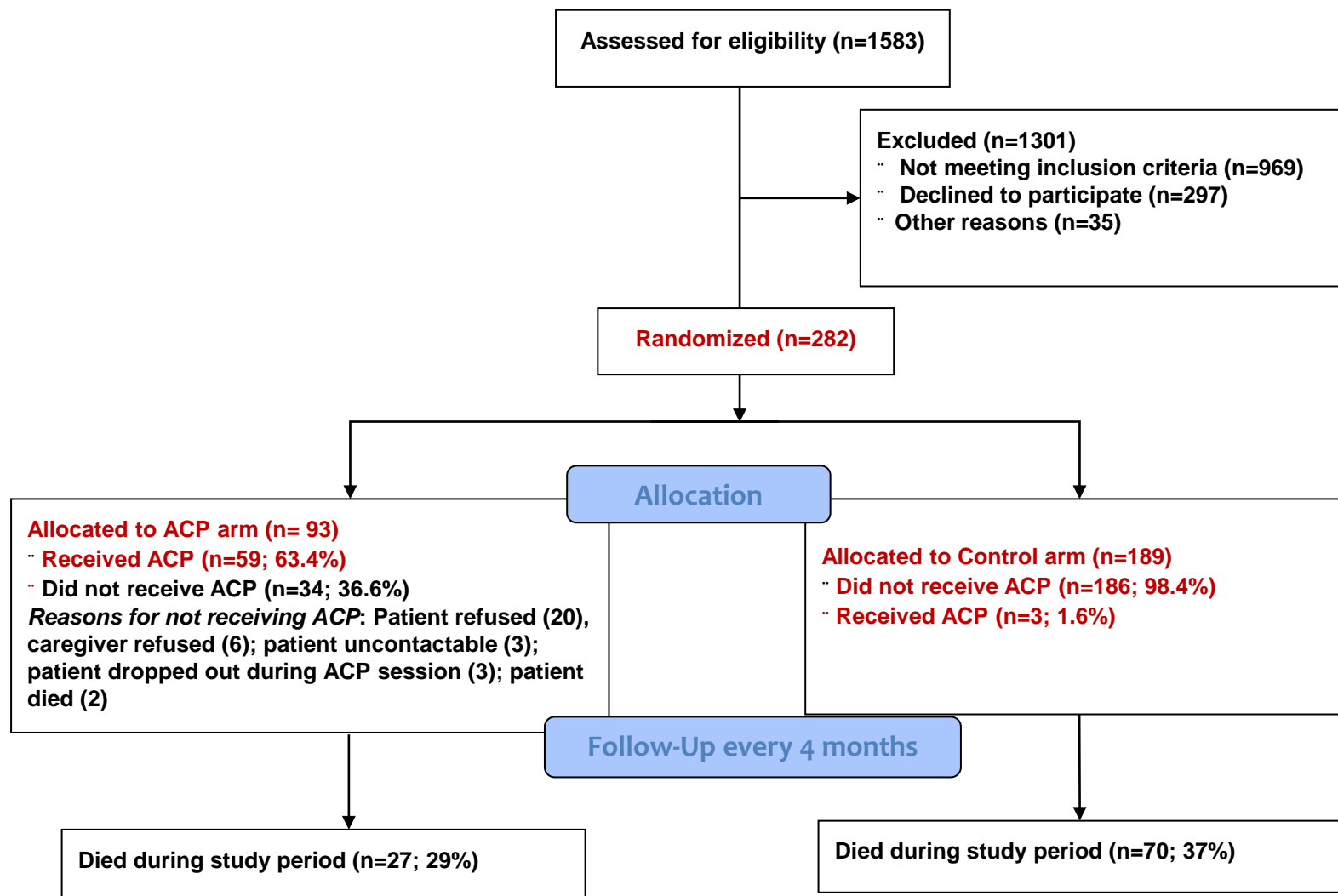
# Aims

- **Primary aim:** Assess whether patients in the ACP arm have a greater likelihood of receiving EOL care consistent with their preferences compared to patients in the control arm (sub-sample: deceased patients)
- **Secondary aims:** Compare between ACP and control arms – patient-surrogate discussions of EOL preferences, decisional conflict, understanding of illness, anxiety, depression, quality of life

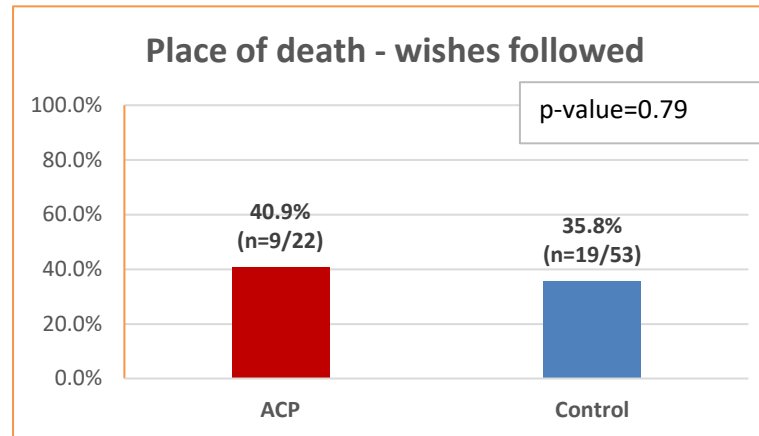
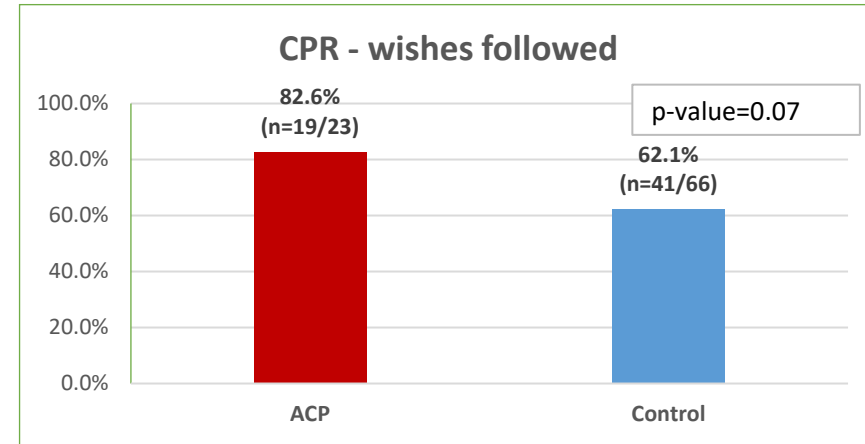
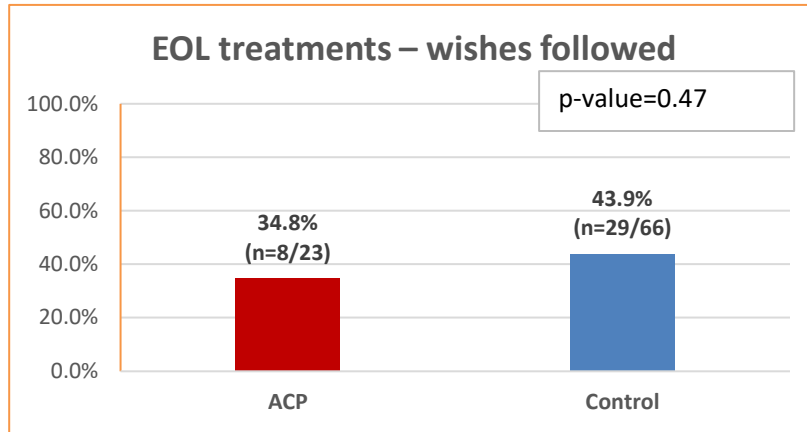
# ACP Evaluation Design

- Eligible patients: Inpatients with a diagnosis of Heart Failure and New York Heart Association classification III and IV symptoms, 21 years and older and able to give informed consent
- Study sites: National Heart Centre and Singapore General Hospital (Department of Internal Medicine)
- Follow-up survey every 4 months for 2 years

# Flow Diagram showing enrollment and follow-up (Study period: March 2015-June 2018)



# EOL care consistent with stated preference (deceased patients)

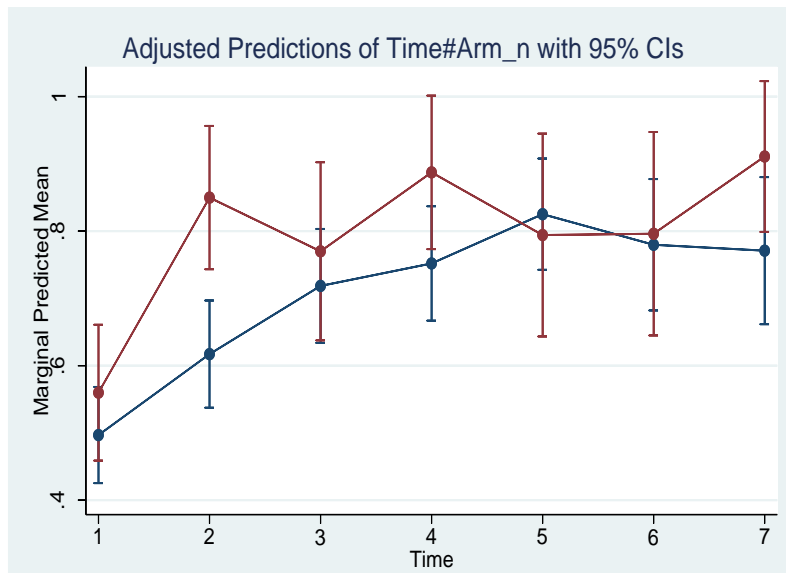


The proportion of patients receiving **EOL treatments** consistent with their stated preferences is **not significantly** higher in the ACP arm compared to the control arm

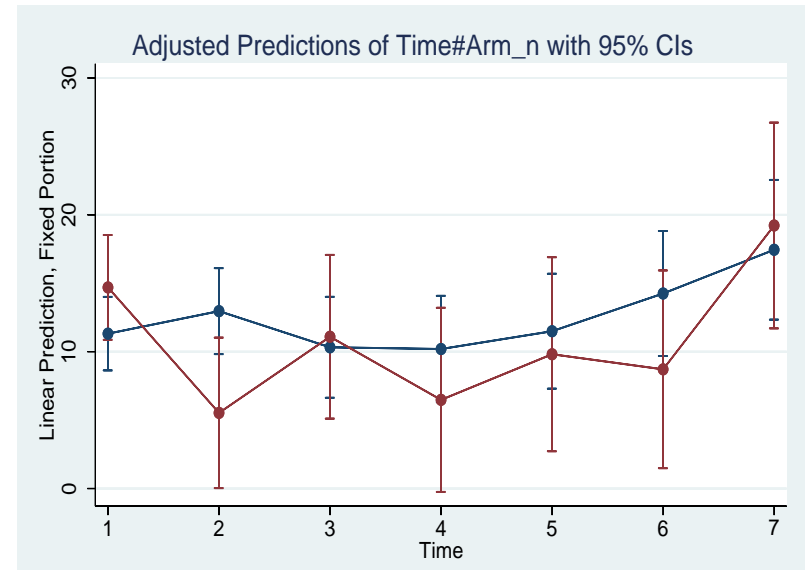


# Patient discussion of care preferences with their surrogates and decisional conflict

## Discussion with surrogates



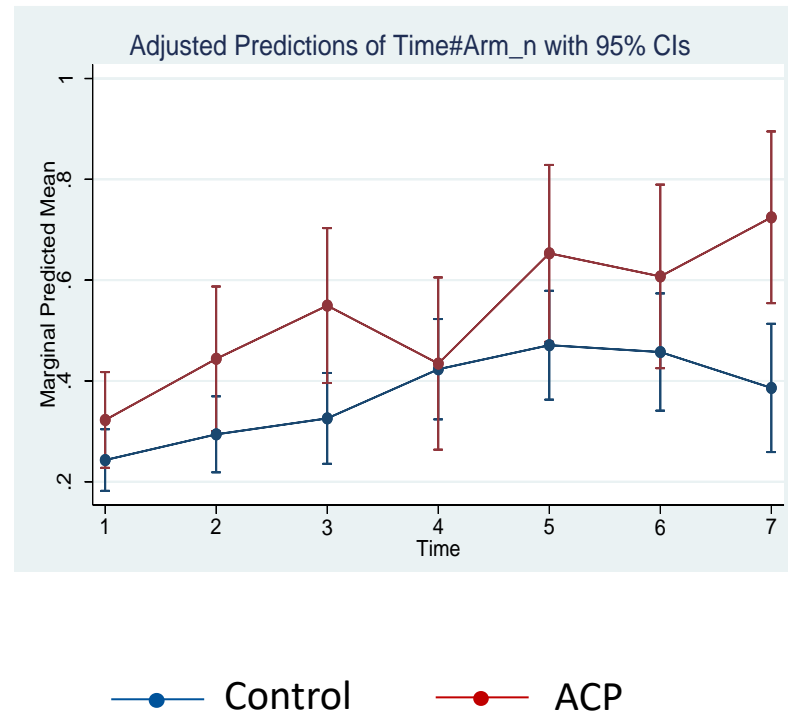
## Decisional conflict



—●— Control —●— ACP

**ACP had short-term benefits in improving patient decision making**

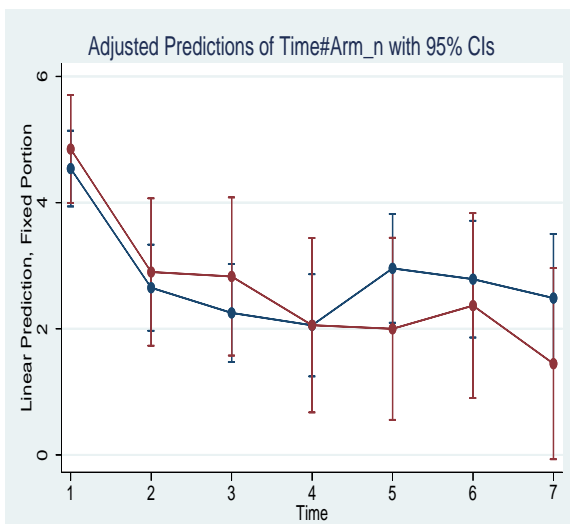
## Compare patient's understanding of illness between two arms



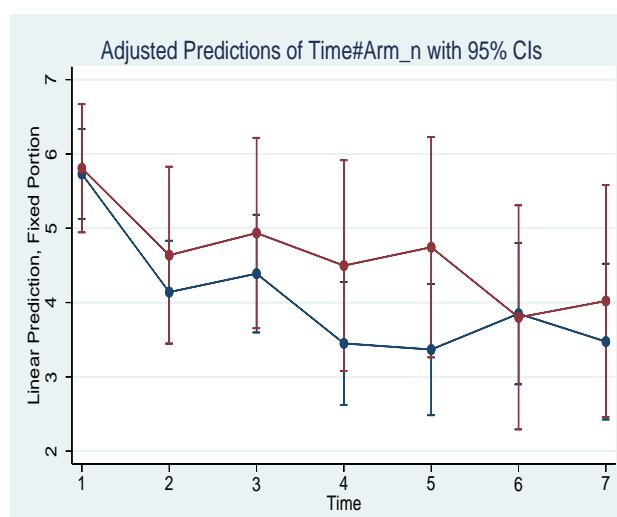
**ACP did not influence patient understanding of illness**

# Compare patient's anxiety, depression and quality of life between two arms

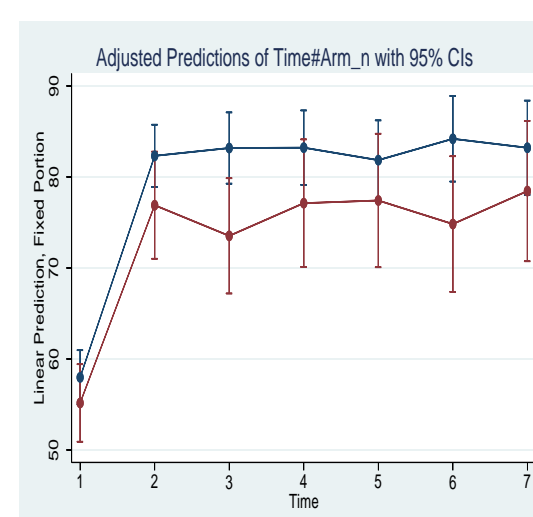
## Anxiety



## Depression



## Overall Quality of life



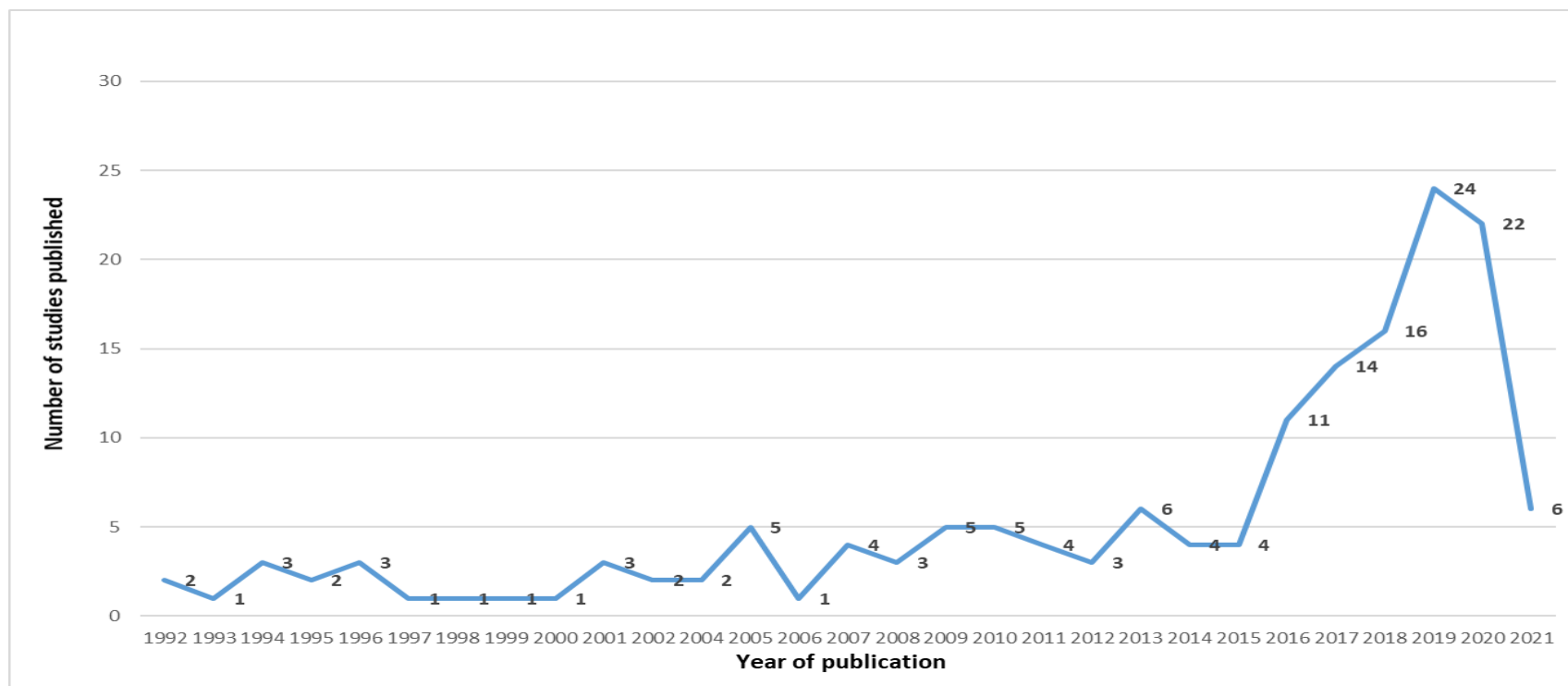
—●— Control —●— ACP

**ACP did not influence patient's anxiety/depression or quality of life (no harm)**

# Key points

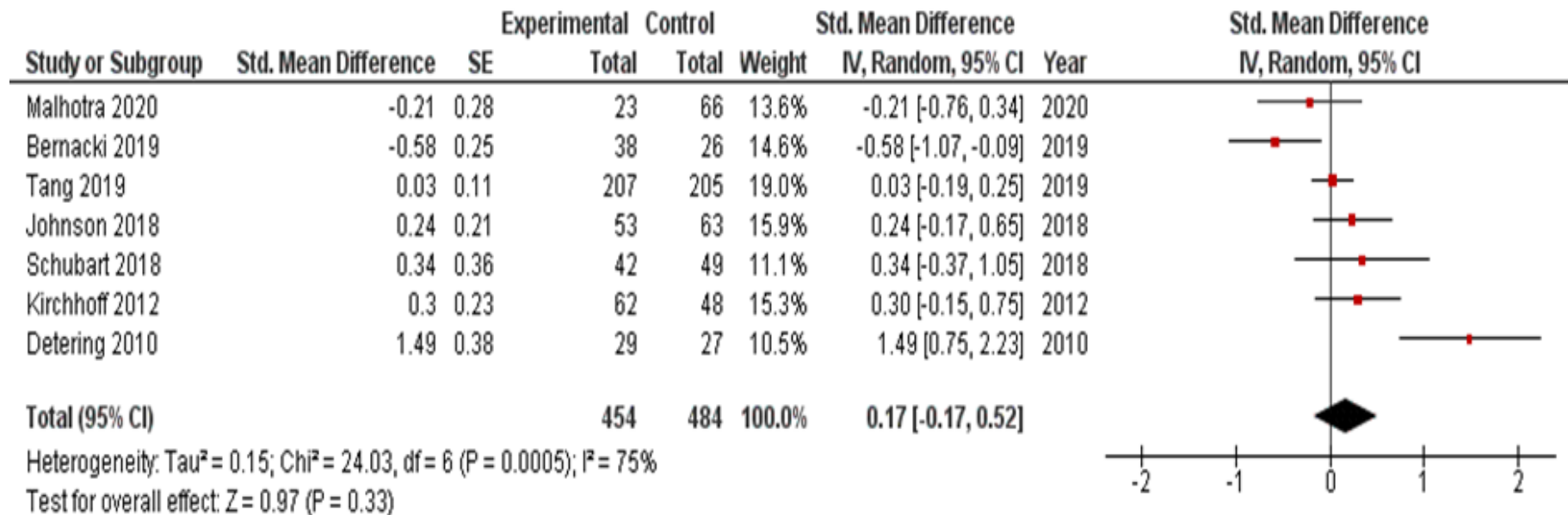
- No conclusive evidence that the current model of ACP, as implemented, for patients with HF improves the likelihood of them receiving EOL treatments consistent with their wishes
- ACP had short-term benefits in improving patient decision making.
- ACP did not influence patient's anxiety/depression or quality of life

# We conducted a systematic review of all RCTs conducted till date



159 RCTs published between 1992 and 2021

# Meta-analysis for the outcome – goal concordant care



**Effect size was small and not significant  
 (SMD [95% CI]: 0.17 [-0.17, 0.52])**

# Other outcomes

- Patient quality of life – None of the 14 RCTs showed improvement
- Patient mental health – 4 of the 19 RCTs showed improvement
- Health care use/costs – 4 of the 22 RCTs showed reduction



# Possible reasons

- Family, physician, organizational and policy related factors.
- Instability in patient preferences

# Imagine going for grocery shopping empty stomach



We make decisions that satisfy our preferences that exist in the present but not in the future.

# Projection bias



Problematic when there is a mismatch between how we are feeling right now and how we will feel in the future

# Studies on projection bias

- Christensen-Szalanski, 1984 – Women's decisions during child birth for analgesia:
  - 1 month before labour, during early labour - avoid analgesia
  - During labour –wish for analgesia
  - 1 month after labour – avoid analgesia

It was not the experience of childbirth per se that affected women's decisions but their inability to appreciate, when they were free of pain, how the pain of labour was likely to affect their preferences for analgesia

# Fluctuations in will to live

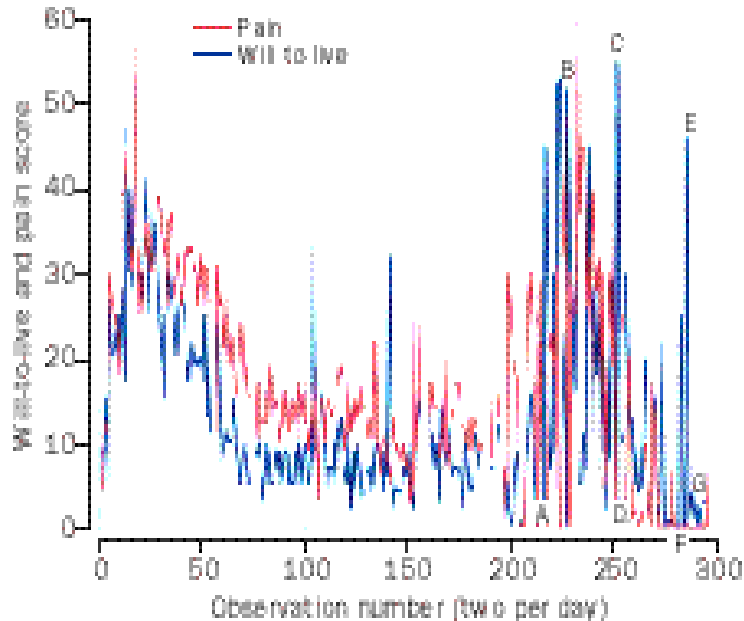


Figure 1: **Will-to-live and pain scores in an 82-year-old woman with colorectal cancer**

Maximum 12 h change=C-D; maximum 24 h change=E-F; maximum 7-day change=A-B; maximum 30-day change=B-G.

Chochinov et al. Lancet 1999

Patients' will to live was highly dependent on their immediate feelings of discomfort and distress rather than a long-term assessment of their medical condition or happiness

Health care providers should not be making drastic decisions based on a momentary assessment of patient preferences

We assessed stability in patient preference for EOL care

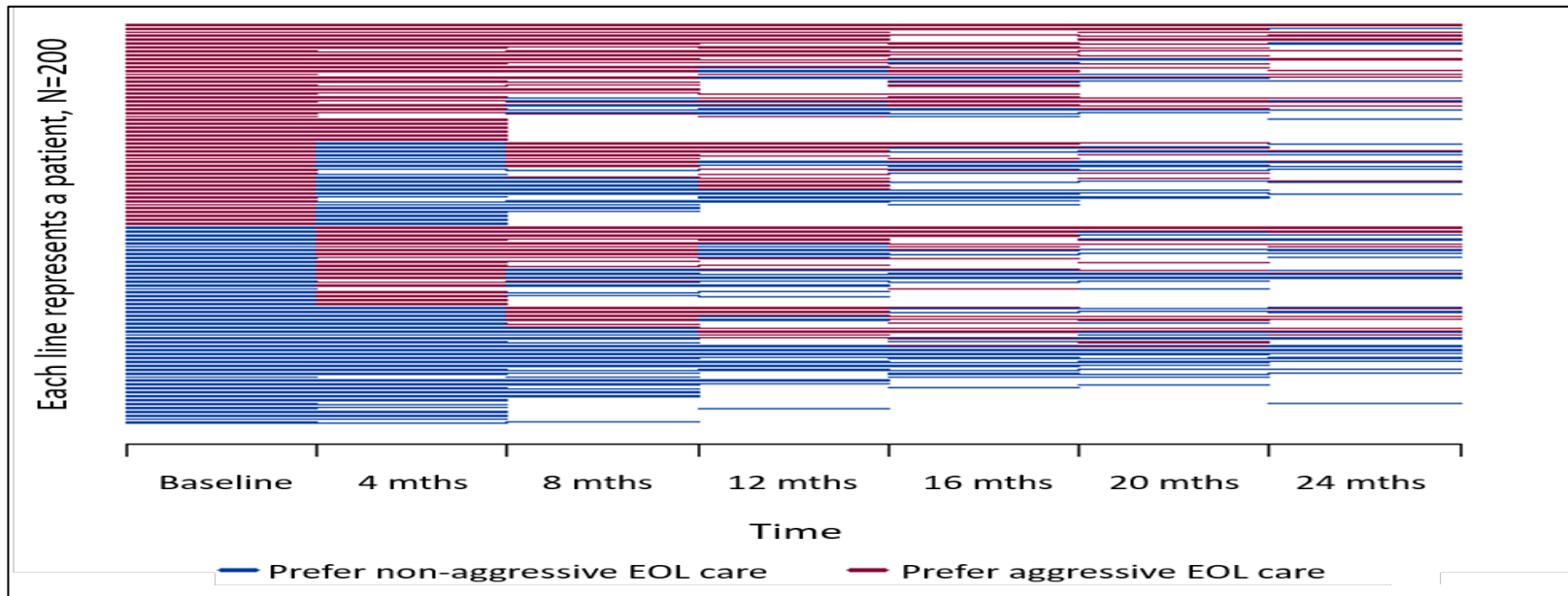
- Patients with advanced heart failure

# Preference for EOL care

- Aggressive care
  - full treatment including intubation, mechanical ventilation, cardioversion and transfer to intensive care
- Non-aggressive EOL care
  - limited additional treatment - limited trial of treatment, oral or intravenous medications, non-invasive ventilation support and transfer to hospital
  - comfort care- medications, oxygen and other measures used for comfort at the place where the patient lives

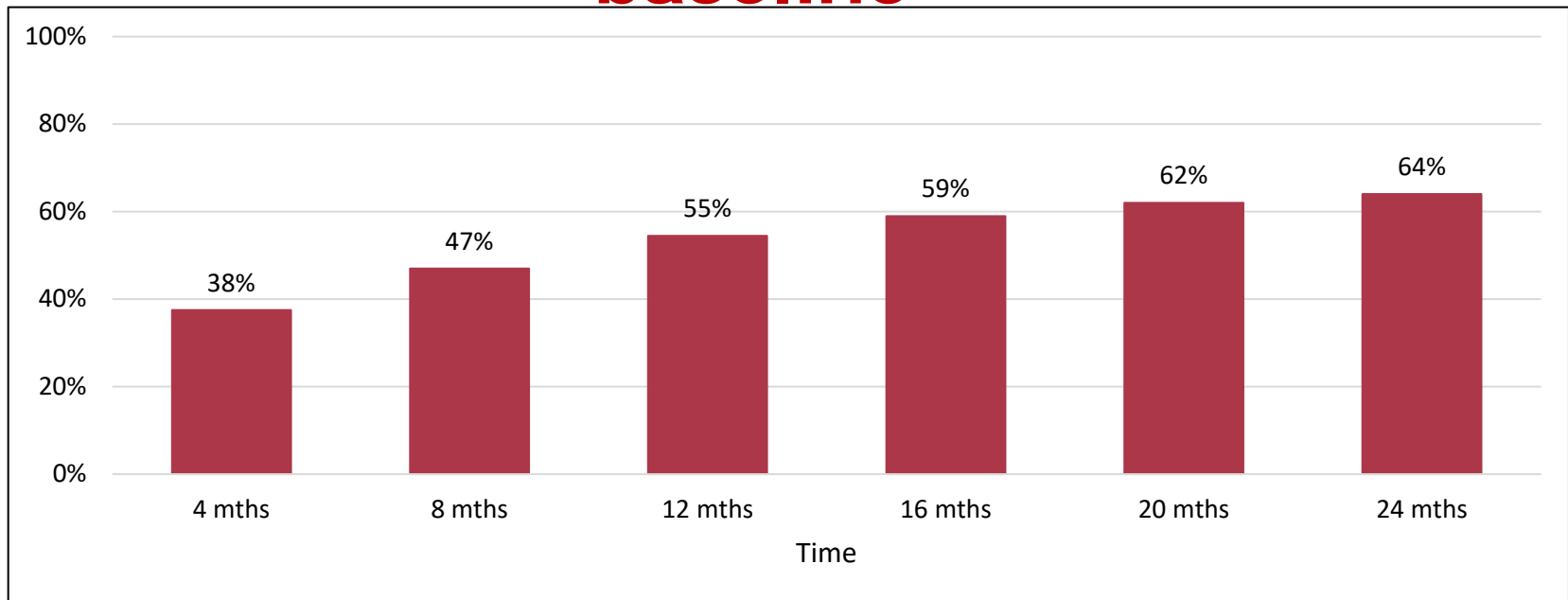


# Instability in preference for aggressive end of life care



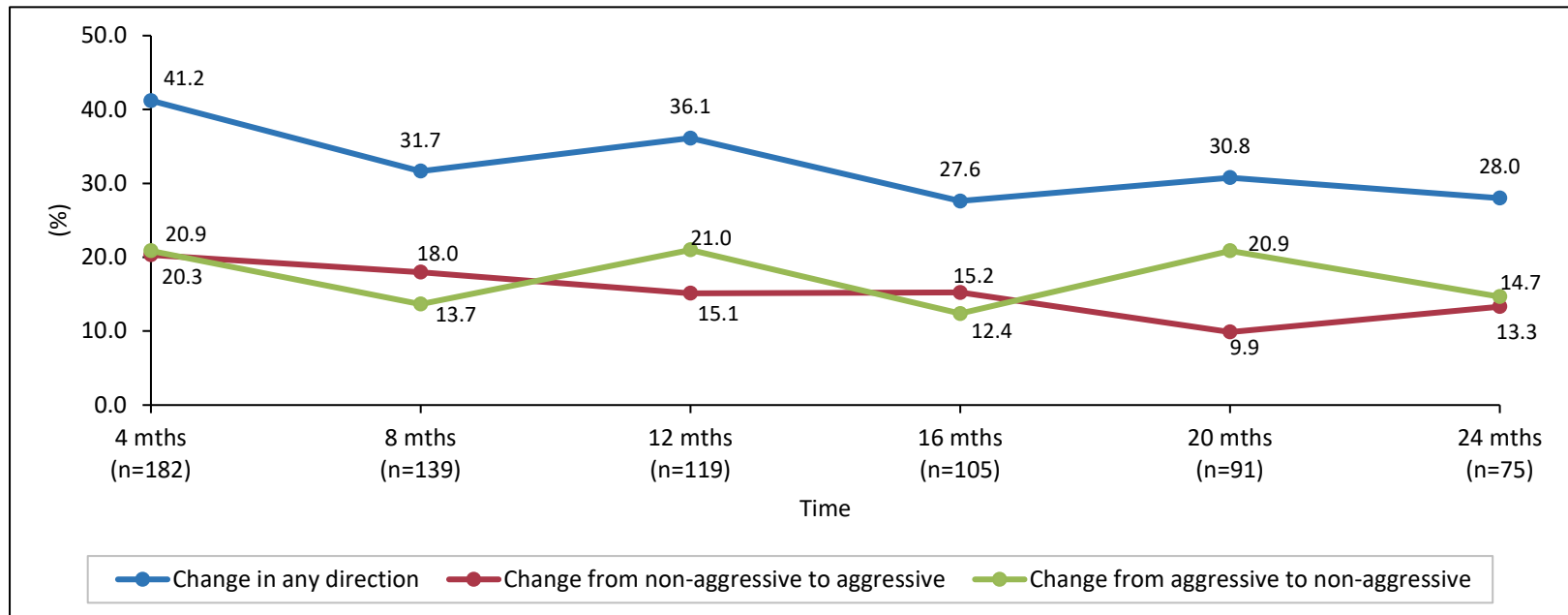
- At baseline, half of the patient sample preferred aggressive EOL care
- Many horizontal lines change in color indicating that these patients change their stated preference for EOL care over time.

# Proportion of patients who changed EOL care preference at least once since baseline



- Even at 4 months, more than a third of their patients changed their end of life care preference
- Overall 64% of patients changed their preferred EOL care during follow-up period

# Change in stated preference for EOL care over time



- Patients' stated preference can change in any direction (i.e. from aggressive to non-aggressive EOL care and vice-versa)
- For most waves, almost an equal proportion of patients changed their stated preference in either direction

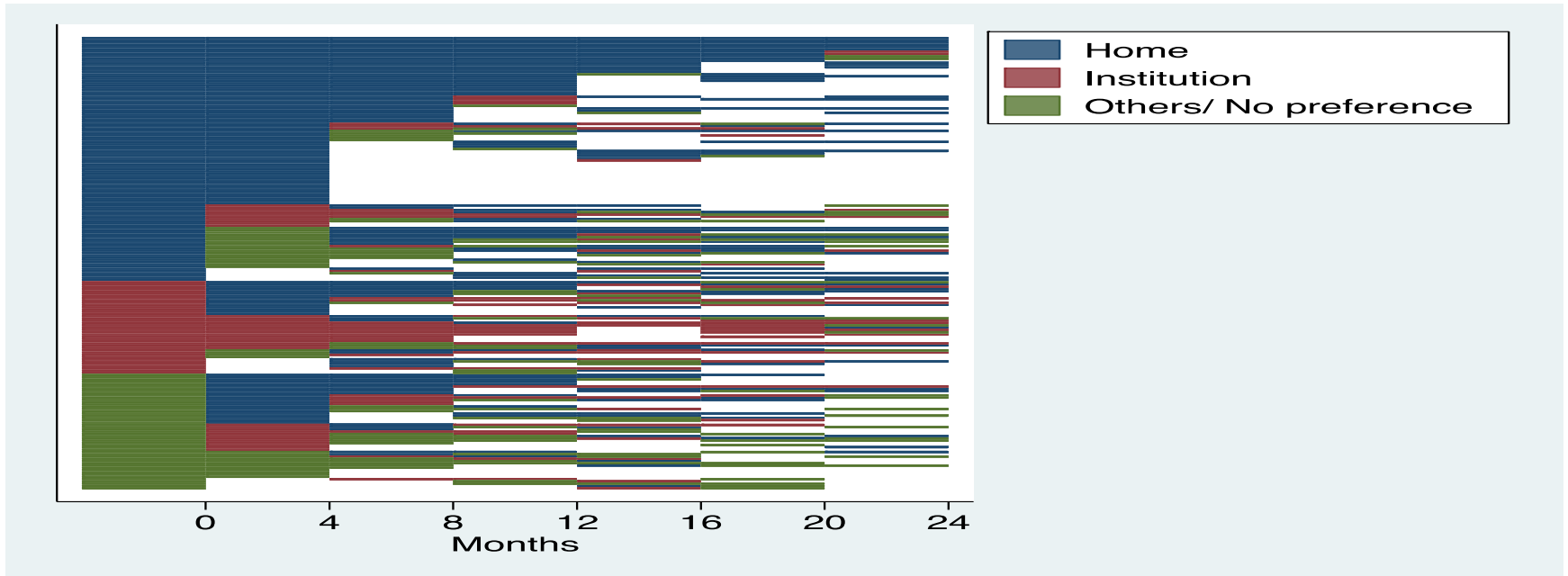
# Association between time-varying covariates and EOL care preferences

- Patients who correctly understood their prognosis were
  - less likely to prefer aggressive EOL care (OR: 0.53; p: 0.001)
  - less likely to change their preference from non-aggressive to aggressive EOL care (OR: 0.66; p-value: 0.07)
- No association between receipt of ACP and change in preferred EOL care

# **We also examined preferred place of death**

- We asked patients their preferred place of death – home, institution (hospital, hospice, nursing home) and unclear preference
- We assessed change in preferred place of death:
  - Change to a preference for home death
  - Change to a preference for institutional death
  - Change to an unclear preference

# Instability in preference for place of death among heart failure patients



- Patients changed their preferred place of death over time

# Association with time varying factors

- Patients' correct prognostic understanding reduced the relative risk of change in preferred place of death to home (RRR: 0.50, 95% CI: 0.32, 0.77)
- Patients' higher quality of life was associated with a lower relative risk of patients changing their preferred place of death to an institution (RRR: 0.99, 95% CI: 0.98, 1.00) relative to no change in preference.

## **We also studied patients with advanced cancer**

- We recruited 600 patients with Stage IV cancer as part of a cohort study titled “Cost of Medical Care of Patients with Advanced Serious Illness in Singapore (COMPASS)”
- Patients recruited from National Cancer Centre Singapore and National University Hospital Singapore
- Surveyed every 3 months till patient’s death



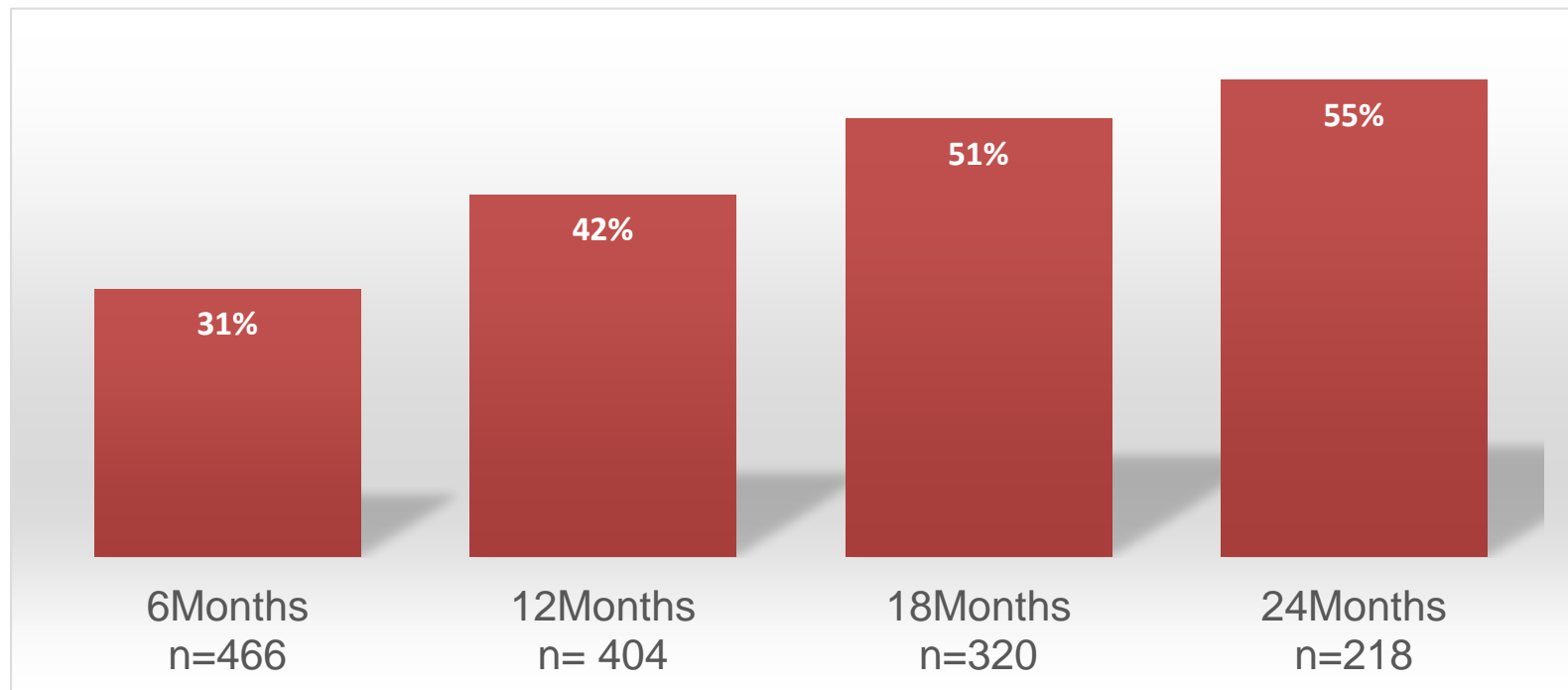
# COMPASS

- 466 patients answered the survey at least two points
- At baseline-
  - 64% - preferred home death,
  - 12% - preferred institutional death (9.7% hospital, 2.2% hospice and 0.6% nursing home)
  - 22% - no clear preference.

# COMPASS

- We assessed change in preferred place of death:
  - Change to a preference for home death
  - Change to a preference for institutional death
  - Change to an unclear preference

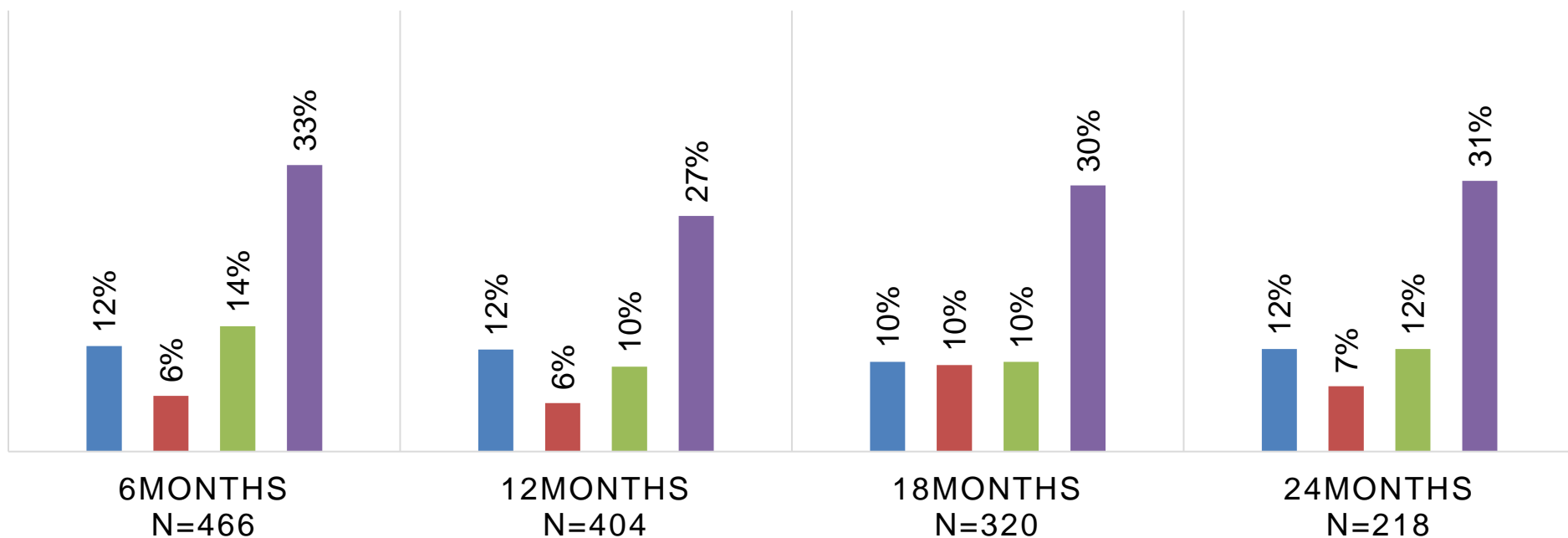
# Proportion of patients who changed their preferred place of death at least once since baseline



More than 40% of the patients changed their preferred place of death in 1 year

# Change in preferred place of death from previous time point

Change to Home   Change to Institution   Change to Unclear   Any change



More than a quarter of patients changed their preferred place of death every 6 months with no clear trend in change towards home or institution

# Impact of time-varying covariates change in preferred place of death

- Patients **psychologically distressed** at the time of survey were more likely to change their preferred place of death to home (RRR: 1.81; 95% CI: 1.16-2.82) and to institution (RRR 2.00; 95% CI: 1.17-3.42) relative to no change in preference.
- Patients **hospitalized in the last 6 months** were more likely to change their preferred place of death to home (RRR 1.53; 95% CI 1.04-2.24) and less likely to change to institution (RRR 0.53; 95% CI 0.30-0.92) relative to no change in preference.

# Conclusion

- Preference is constructed at that point in time. Dependent on the context – mood, health, information available at that point in time

We also assessed the relationship between preferences for life-extending treatments and overall goal of care

# Prospective Longitudinal Study of Caregivers of Community Dwelling Persons with Severe Dementia (PISCES)

- As part of the PISCES cohort study, we conducted a qualitative study with caregivers of people with severe dementia (FAST 7)
- 26 in-depth interviews with primary informal caregivers

Malhotra C et al. A prospective longitudinal study of caregivers of community dwelling persons with severe dementia (PISCES): Study protocol. Journal of Alzheimer's Disease. 2020: 403 – 416.



# PISCES

In the survey, we asked caregivers about their overall goal of care for person with severe dementia

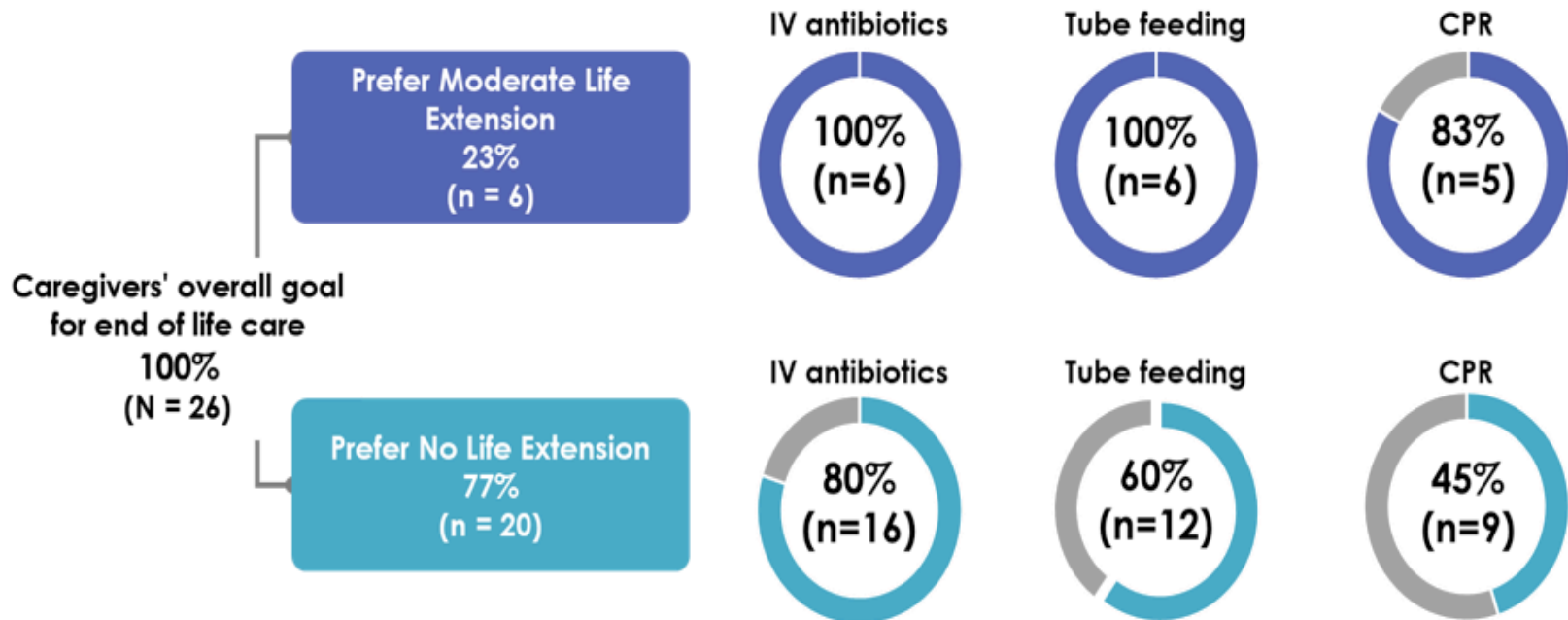
- Would you prefer treatments that extend life as much as possible or those that give high quality of life?
  - 1 =extend life as much as possible with low quality of life
  - 9 =no life extension with high quality of life
    - Midpoint 5 indicated moderate life extension with moderate quality of life

# PISCES

- During the qualitative interview, we asked caregivers reasons for their stated goal of care
- We also elicited their preference for three potentially life-extending interventions –
  - IV antibiotics - in the event of hospitalization with life-threatening infection like pneumonia
  - Nasogastric tube feeding (the predominant modality for tube feeding in Singapore in case of dysphagia)
  - Cardiopulmonary resuscitation (CPR)

# Preferences may not be consistent with overall goals for care

Caregivers' preference for potentially life-extending interventions



# Reasons for discordance

- Fear of regret about making 'wrong decision'

*I [am] already regretting... I did not agree to the dementia medication that resulted in...has advanced her dementia. So if I deny her and she passes on, then I'll be regretting right?...my decision will be more...to that point then I will not have the regrets that I had in the beginning of her dementia.  
(Daughter)*

# Reasons for discordance

- Considered interventions to address immediate needs even when long-term goal did not match providing that intervention

*Overall goal of care:*

- *I don't want her to be in pain, I don't want her to suffer...if the price is pain, suffering, no quality of life but just stretching it, then no...if it's going to cost her more suffering, more discomfort, then I think I cannot be selfish...*

*With reference to IV antibiotics:*

- *I have agreed that we will take her to the hospital but we will not do anything that will make her more uncomfortable or in pain...but when push comes to shove, if she needs medical attention, I will say give (antibiotics)... it's very difficult for me I know and I'm rescinding on that agreement we made amongst ourselves...if there's a condition like medical ailment that can be treated, it needs to be treated. That's it. Period.*

Caregivers are willing to forego their overall goals in favour of immediate demands

# Reasons for discordance

- Anticipated disagreement with other family members on overall goal of care

*My brother said to let her try when asked at the hospital...my initial thoughts were to not let her suffer because she is already in this age. But my brother was against it, he say cannot, must try... not letting her eat would mean that it's the end for her right. He also cannot bear to do it... (Daughter)*

# Conclusion

- Preferences are not only unstable with time, they are also not always consistent with prior values/goals.
- Studies provide indication that patients (and caregivers) do not hold well-formulated strongly held views on what forms of end of life care they want.

# Implications for advance care planning

- If patient preferences are documented and never updated as their illness changes course, there is a high likelihood that preferences recorded are not valid at the time of EOL decision making.



# Implications for advance care planning

- Is it even possible to know with certainty what a patient would have wanted?
- If not, then what is the purpose of ACP?

# Implications for advance care planning

## Viewpoint

October 8, 2021

## What's Wrong With Advance Care Planning?

R. Sean Morrison, MD<sup>1,2</sup>; Diane E. Meier, MD<sup>1</sup>; Robert M. Arnold, MD<sup>3</sup>

» Author Affiliations | Article Information

JAMA. 2021;326(16):1575-1576. doi:10.1001/jama.2021.16430

Journal of Palliative Medicine, Vol. 23, No. 7 | Notes from the Editor

 Free Access

## Advance Directives/Care Planning: Clear, Simple, and Wrong

R. Sean Morrison 

[Ann Intern Med.](#) Author manuscript; available in PMC 2010 Sep 8.

*Published in final edited form as:*

[Ann Intern Med.](#) 2010 Aug 17; 153(4): 256–261.

doi: [10.1059/0003-4819-153-4-201008170-00008](#)

PMCID: PMC2935810

NIHMSID: NIHMS227081

PMID: [20713793](#)

## Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

[Rebecca L. Sudore](#), MD<sup>1</sup> and [Terri R. Fried](#), MD<sup>2</sup>

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# Implications for advance care planning

- For health care providers –
  - Can't assume what is written in an ACP is what patient will want when the time comes unless a patient has consistently expressed the same preference.
  - ACP should be a continuous process of preparation.

# Implications for advance care planning

- We need to rethink the purpose of ACP



# 'My Voice' web tool

- A simple easy-to-do web tool to prepare patients (with heart failure) and their caregivers:
  - Education
  - Choose a surrogate
  - Think about what matters most to them
  - Coaching to discuss these with surrogate and health care providers
  - Update frequently over time

**Thank You**

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