Rethinking Advance Care Planning

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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

Malhotra C et al. Good end-of-life care: perspectives of middle-aged and older Singaporeans. J Pain Symptom Manage. 2012;44(2):252-63

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?	☐	☐

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?	☐	☐

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 [a]
Place of death	Institution >> Home	31,250	67,720 [a]
Pain	Severe pain >> No pain	22,200	76,050 [a]
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[a]

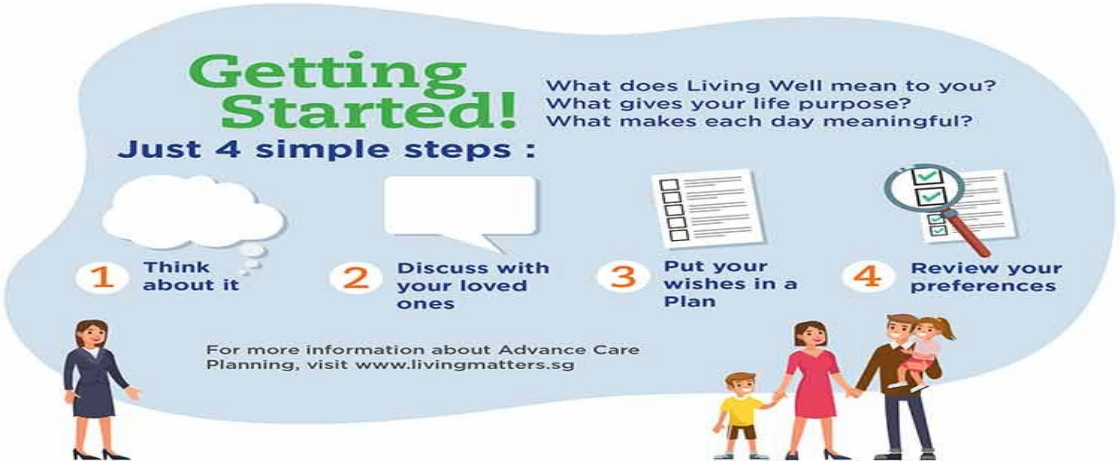
- For patients, extending life is not their top priority
- Caregivers have higher WTPs for all factors other than amount of care

Note: [a] 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.



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

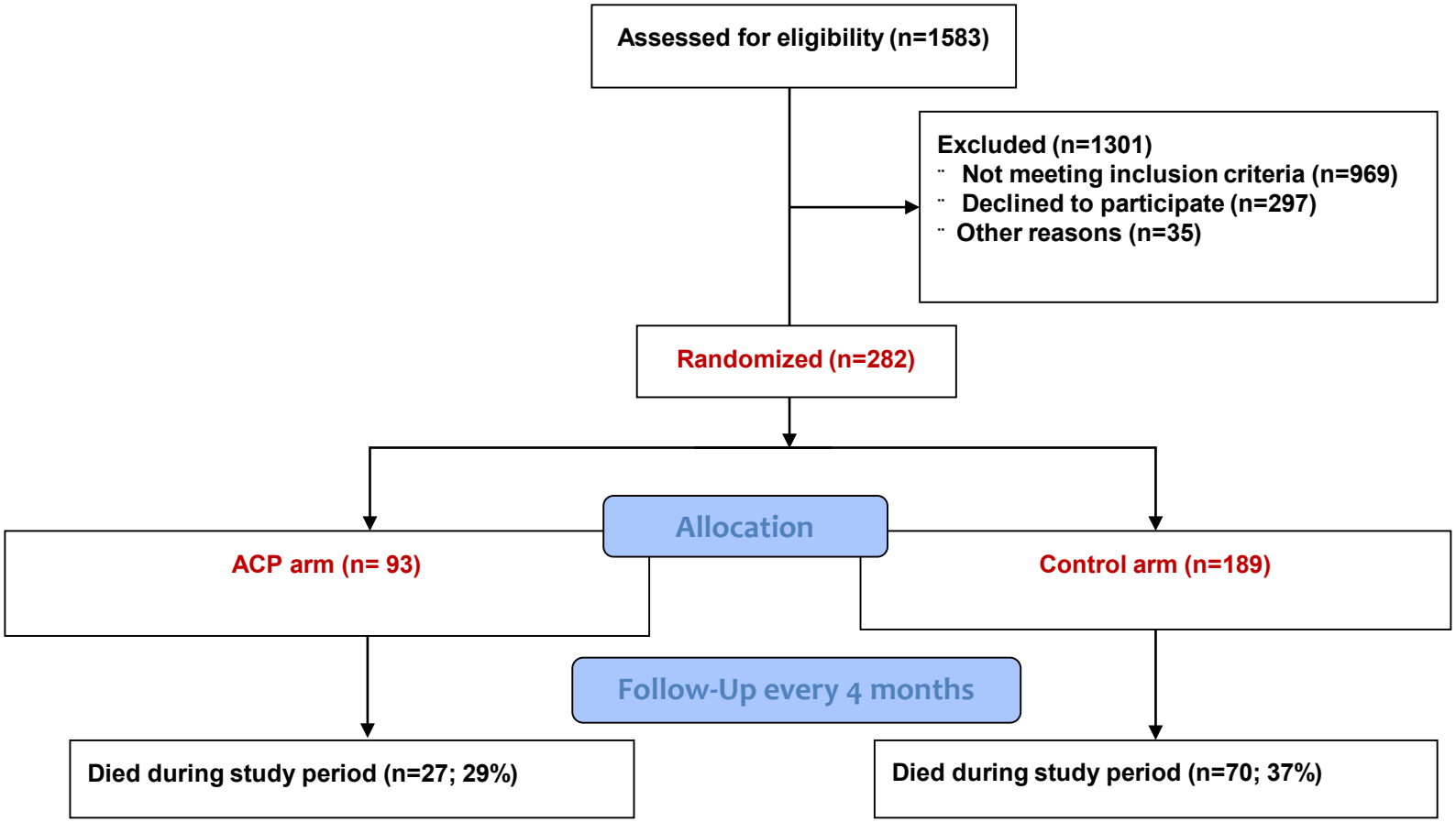
ACP Evaluation Design

- 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

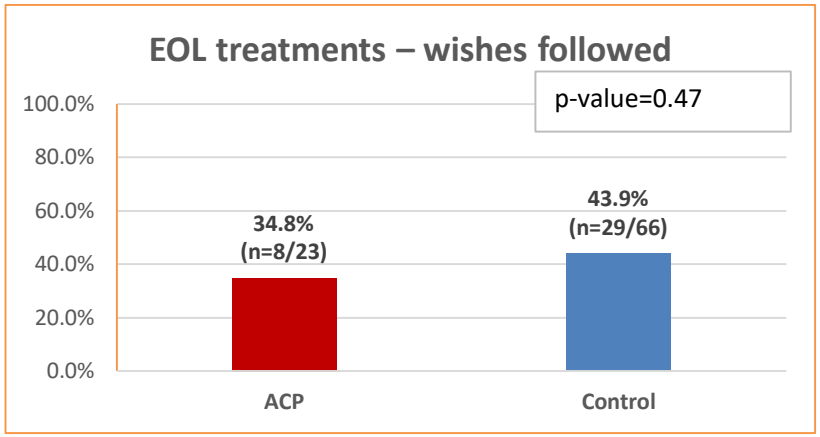
- Study sites: National Heart Centre and Singapore General Hospital (Department of Internal Medicine)

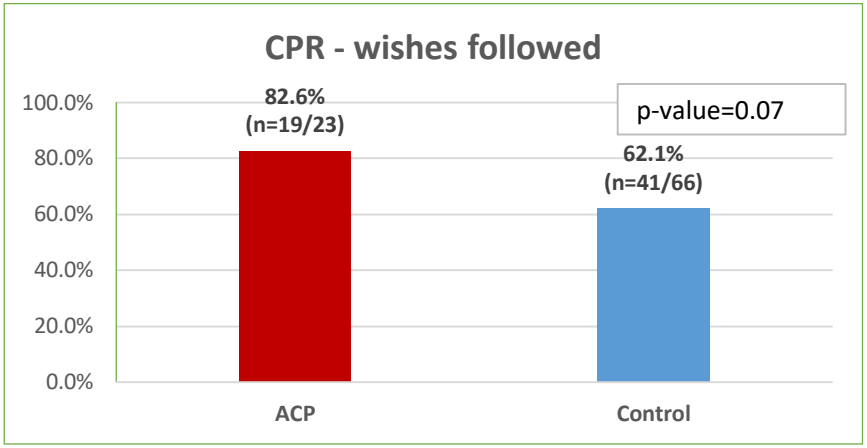
- Follow-up survey every 4 months for 2 years

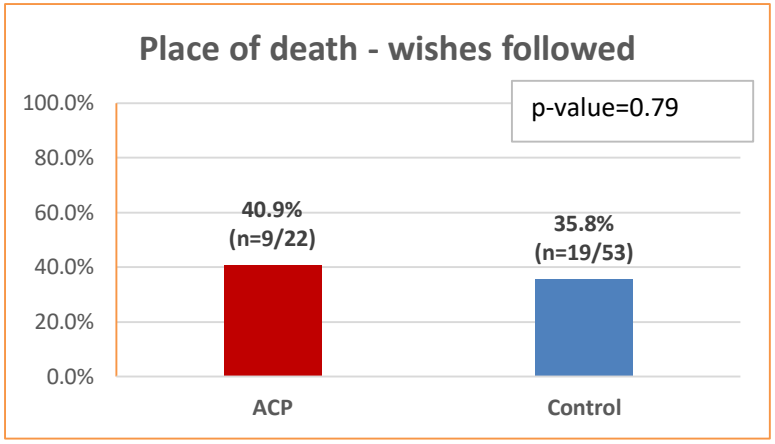
Flow Diagram showing enrollment and follow-up (Study period: March 2015-June 2018)



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

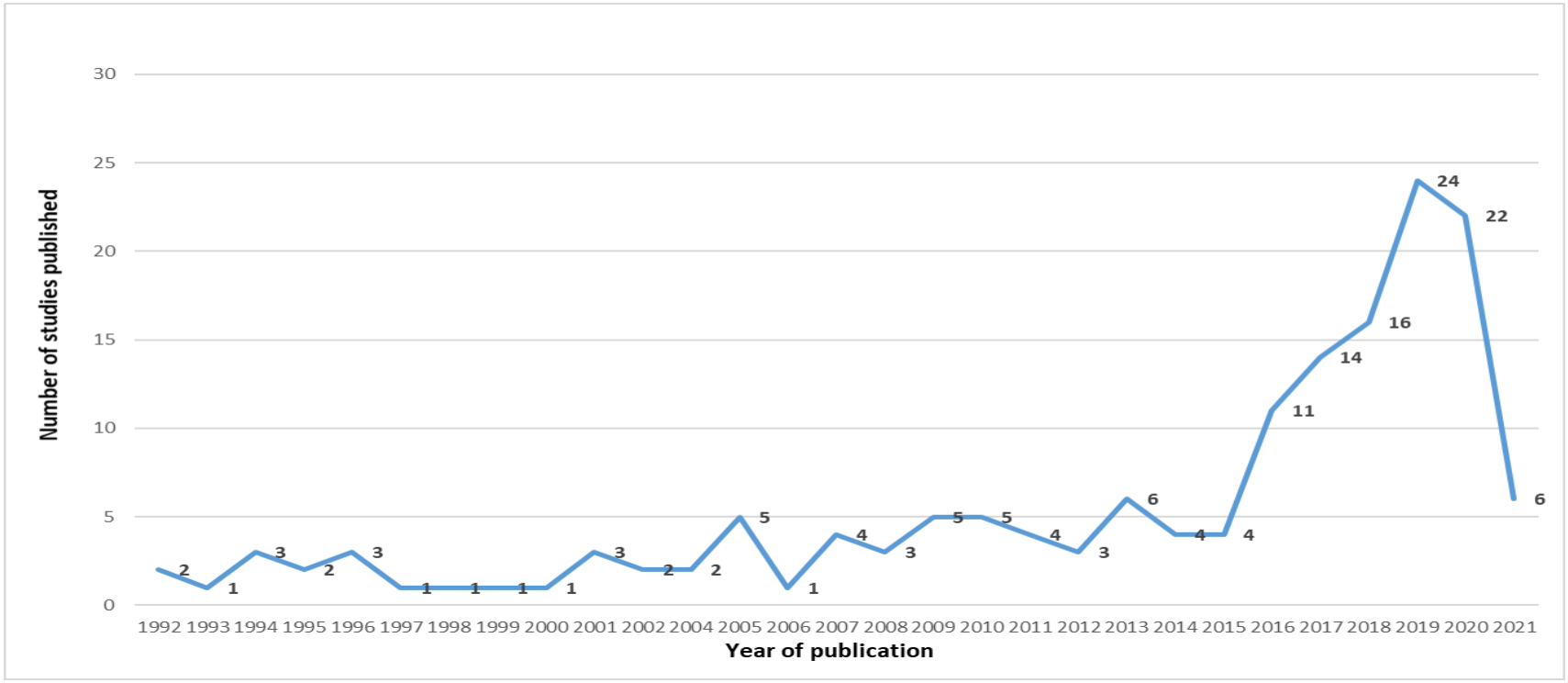
Secondary outcomes

- Short term improvement - Increase in EOL discussions between patients and surrogates, reduction in decisional conflict

- No difference in arms: Anxiety, depressive symptoms, quality of life, patient understanding of illness

HOW ABOUT OTHER SETTINGS?

We conducted a systematic review of all RCTs conducted till 2021



132 RCTs published between 1992 and 2021

Distal patient outcomes

Goal concordant care - 11 RCTs – only 3 showed positive findings, one of which was in elderly inpatients (high-quality) and other two in nursing home residents.

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

Malhotra et al. What is the evidence for efficacy of advance care planning in improving patient outcomes? A systematic review of randomized controlled trials. 2022. BMJ Open.

Proximal patient/caregiver outcomes

- **Quality of patient–physician communication:** 13 of the 19 RCTs showed improvement

Caregiver outcomes:

- **Patient-caregiver congruence in preference**: 18 of the 22 RCTs showed improvement

- **Bereavement outcomes**: 3 of 4 RCTs showed improved outcomes

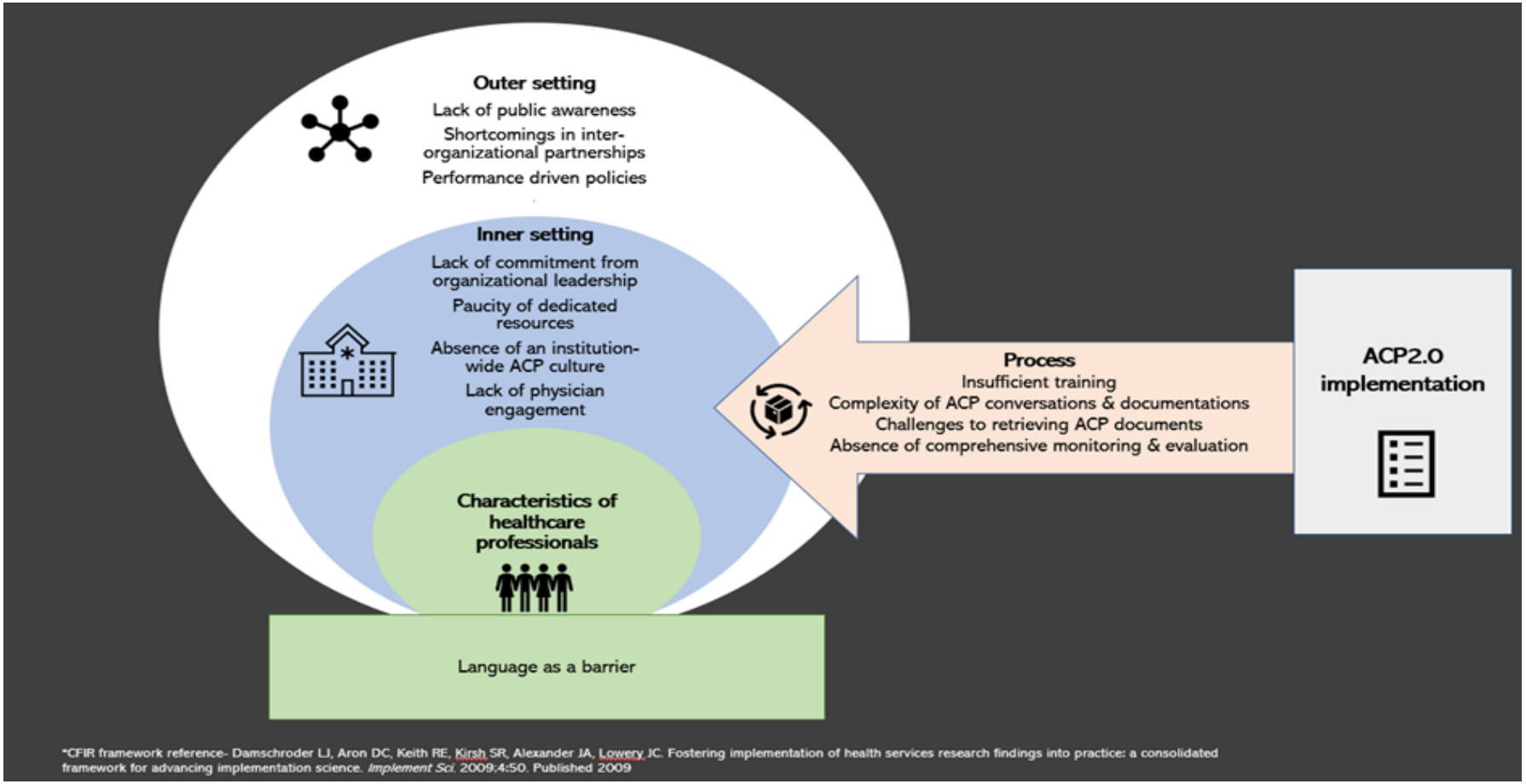
Malhotra C et al. Advance care planning and caregiver outcomes: intervention efficacy – systematic review. *BMJ Supportive & Palliative Care* doi: 10.1136/spcare-2021-003488

Possible reasons

- Individual, organizational and policy factors affecting implementation

- Instability in patient preferences

Individual, organizational and policy factors affecting ACP implementation



Malhotra C, Ramakrishnan C. Complexity of implementing a nationwide advance care planning program: Results from a qualitative evaluation. Age and Ageing

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

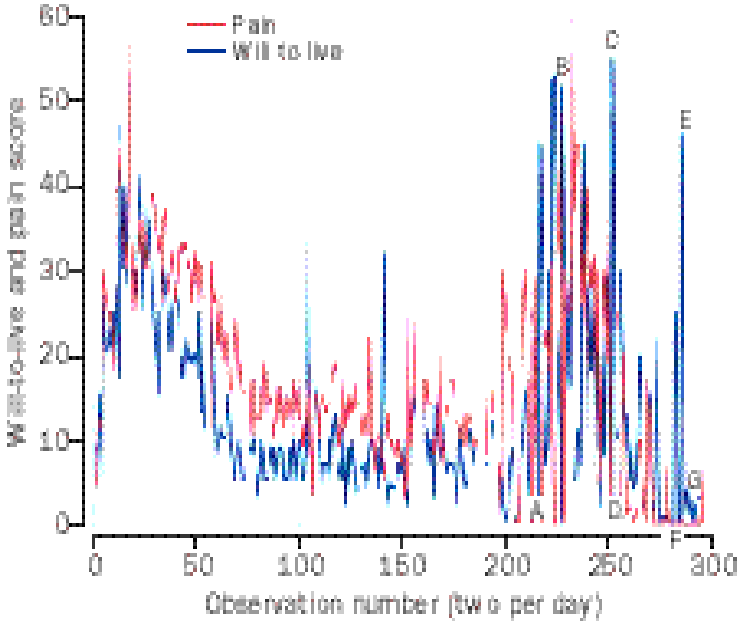


Figure 1: **Will-to-live and pain scores in an 82-year-old woman with colorectal cancer**
Maximum 12 h change=C–D; maximum 24 h change=E–F; maximum 7-day change=A–B; maximum 30-day change=B–G.

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

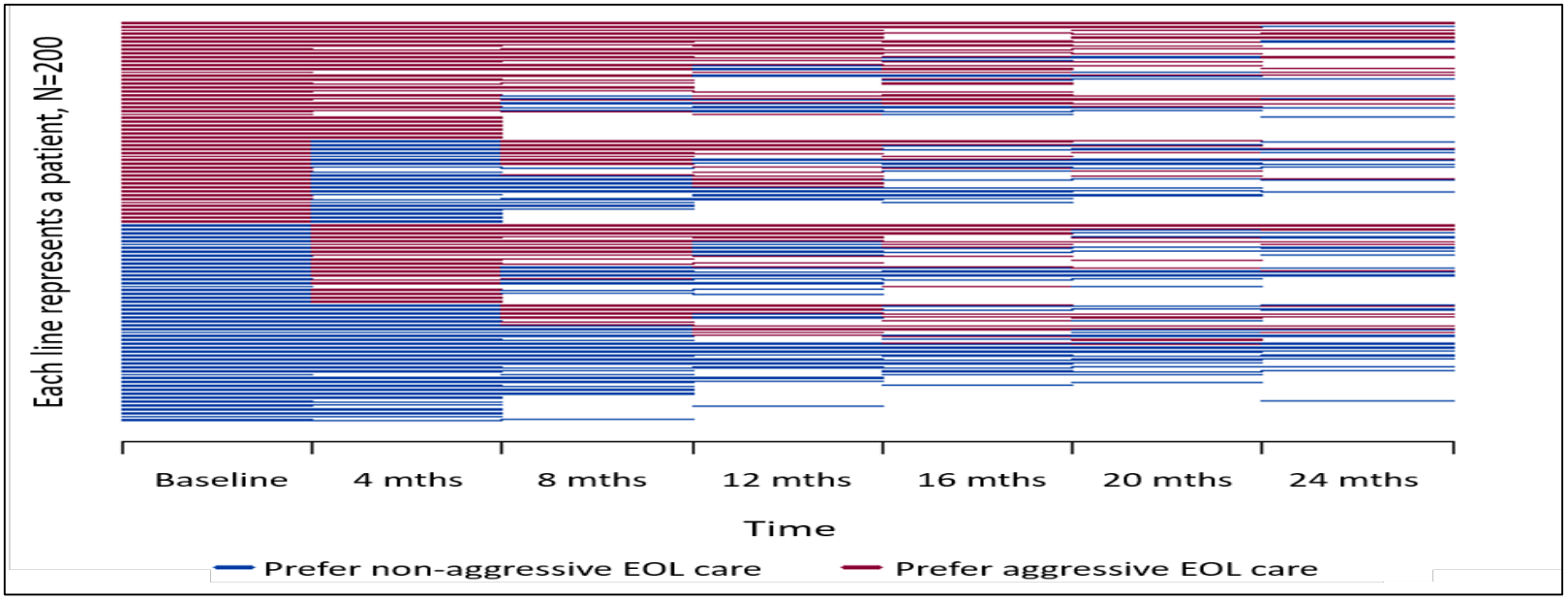
We assessed stability in patient preference for EOL care

- 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

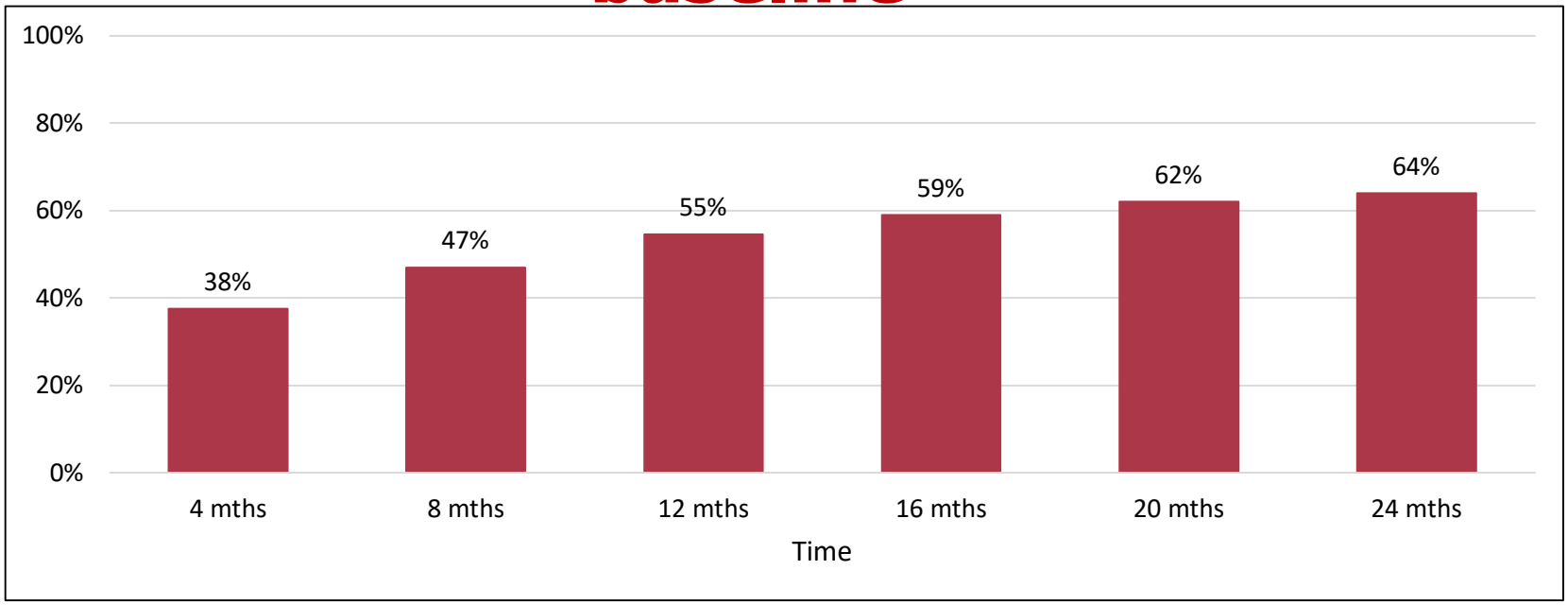
Instability in preference for aggressive end of life care



- 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.

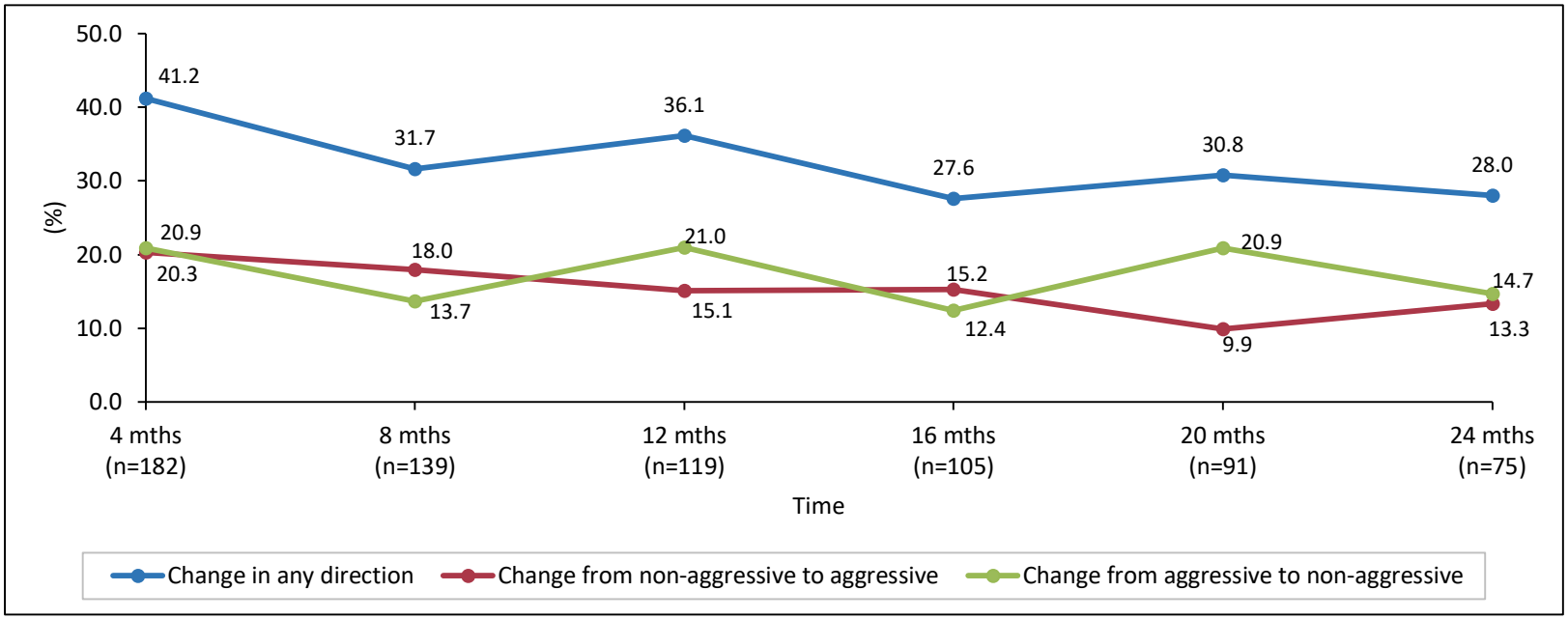
Malhotra C et al. Instability in end-of-life care preference among heart failure patients: Secondary analysis of a randomized controlled trial in Singapore. Journal of General Internal Medicine 2020 Jul;35(7):2010-2016.

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)

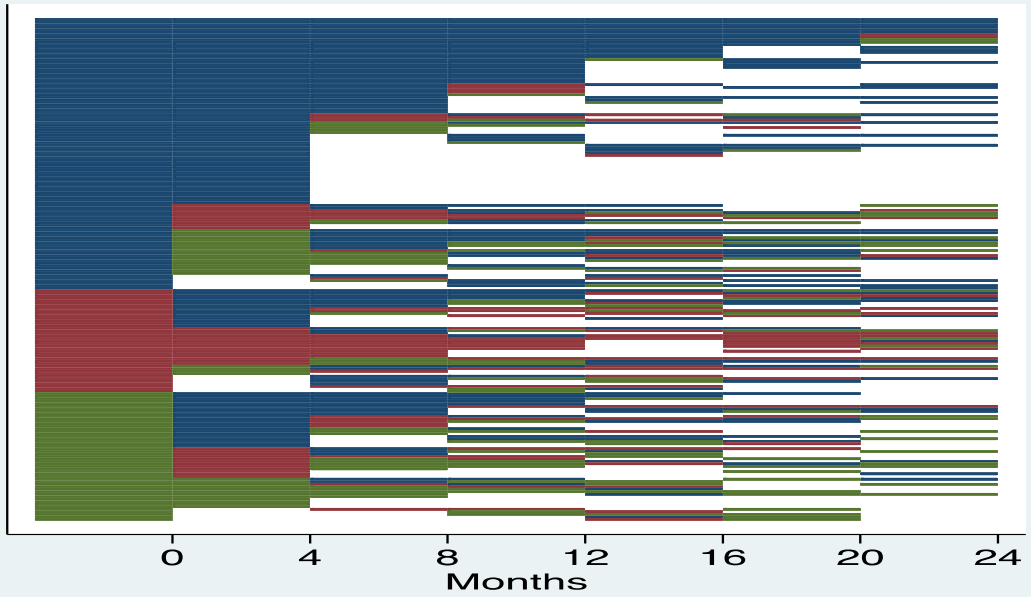
- No association between receipt of ACP and change in preferred EOL care

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

Malhotra C et al. Instability in preference for place of death among patients with symptoms of advanced heart failure. J Am Med Dir Assoc. 2021; 22(2): 349.e29-349.e34

Association with time varying factors

- Correct prognostic understanding and lower quality of life: less likely to want to die at home

We also studied patients with advanced cancer

- 466 patients answered the survey at least two points

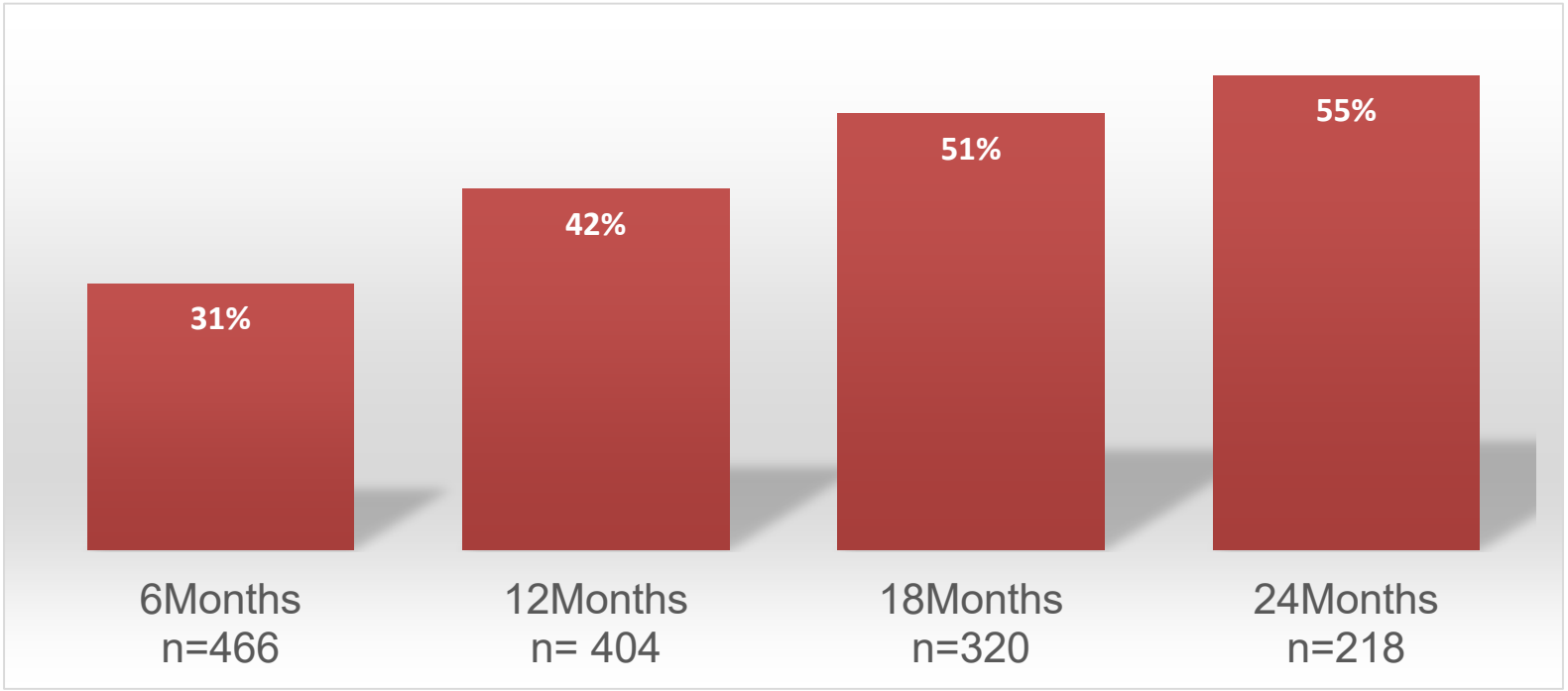
- At baseline-
  - 64% - preferred home death,
  - 12% - preferred institutional death (9.7% hospital, 2.2% hospice and 0.6% nursing home)
  - 22% - no clear preference.

Malhotra C et al. A prospective cohort study of stability in preferred place of death among patients with Stage IV cancer in Singapore. JNCCN—Journal of the National Comprehensive Cancer Network. 2021 Aug 5;jnccn20334. doi: 10.6004/jnccn.2020.7795)

COMPASS

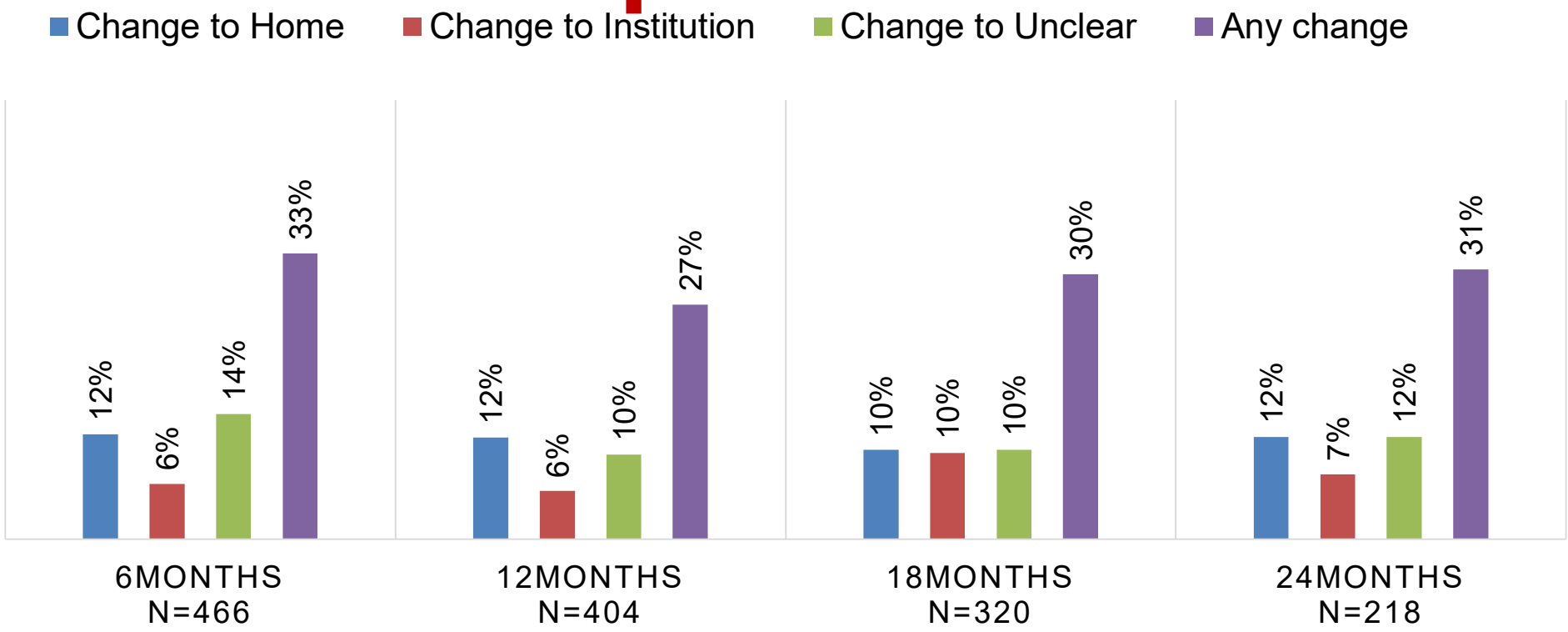
- We assessed change in preferred place of death:
  - Change to a preference for home death
  - Change to a preference for institutional death
  - Change to an unclear preference

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



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 in any direction

- Patients hospitalized in the last 6 months - more likely to change their preferred place of death to home and less likely to change to institution

Conclusion

- Goals and preferences are constructed at that point in time. Dependent on the context – mood, health, information available at that point in time

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.

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[1,2]; Diane E. Meier, MD[1]; Robert M. Arnold, MD[3]

» Author Affiliations | Article Information

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

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Free Access

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

R. Sean Morrison

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PMID: 20713793

Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD[1] and Terri R. Fried, MD[2]

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Implications for advance care planning

- We need to rethink the purpose of ACP

- ACP may not be a magic bullet to reduce health care costs and improve patient quality of life
- But it can be considered a continuous process of preparation for the in-the-moment decision making.

'My Voice' web tool

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

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Thank You

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