

Shared decision making among seriously-ill patients in Singapore

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Shared Decision Making Framework

PATIENT ROLE
(Caregivers)

-Share health history & personal information

-Preference for involvement*
-Trust in clinician

-Process info
-Assess values and preferences

-(Negotiate)
-Make a decision
-Review decision

Information exchange

Defining roles

Deliberation/
Assess preferences

Making a choice

CLINICIAN ROLE

- Identify the problem
-List options

-Assess understanding
-Identify stakeholders

-Encourage questions
-Provide support and info
-Assess preferences

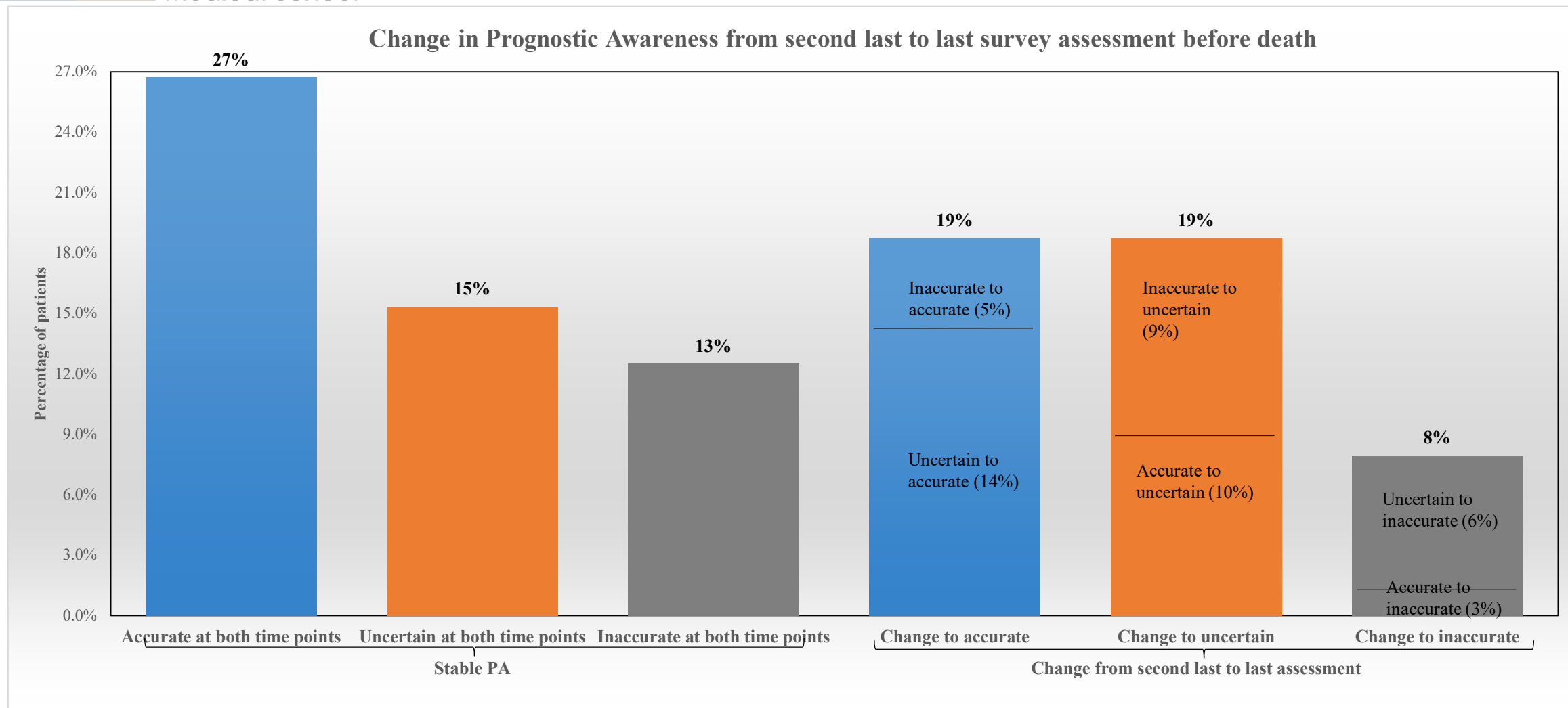
-Review decision
-Follow up

*Understand the decision context and have a choice to involve in DM

Information:

Are terminally-ill patients aware of their prognosis (that their treatments cannot cure their illness)?

Advanced cancer: Patterns of prognostic awareness (N=176)

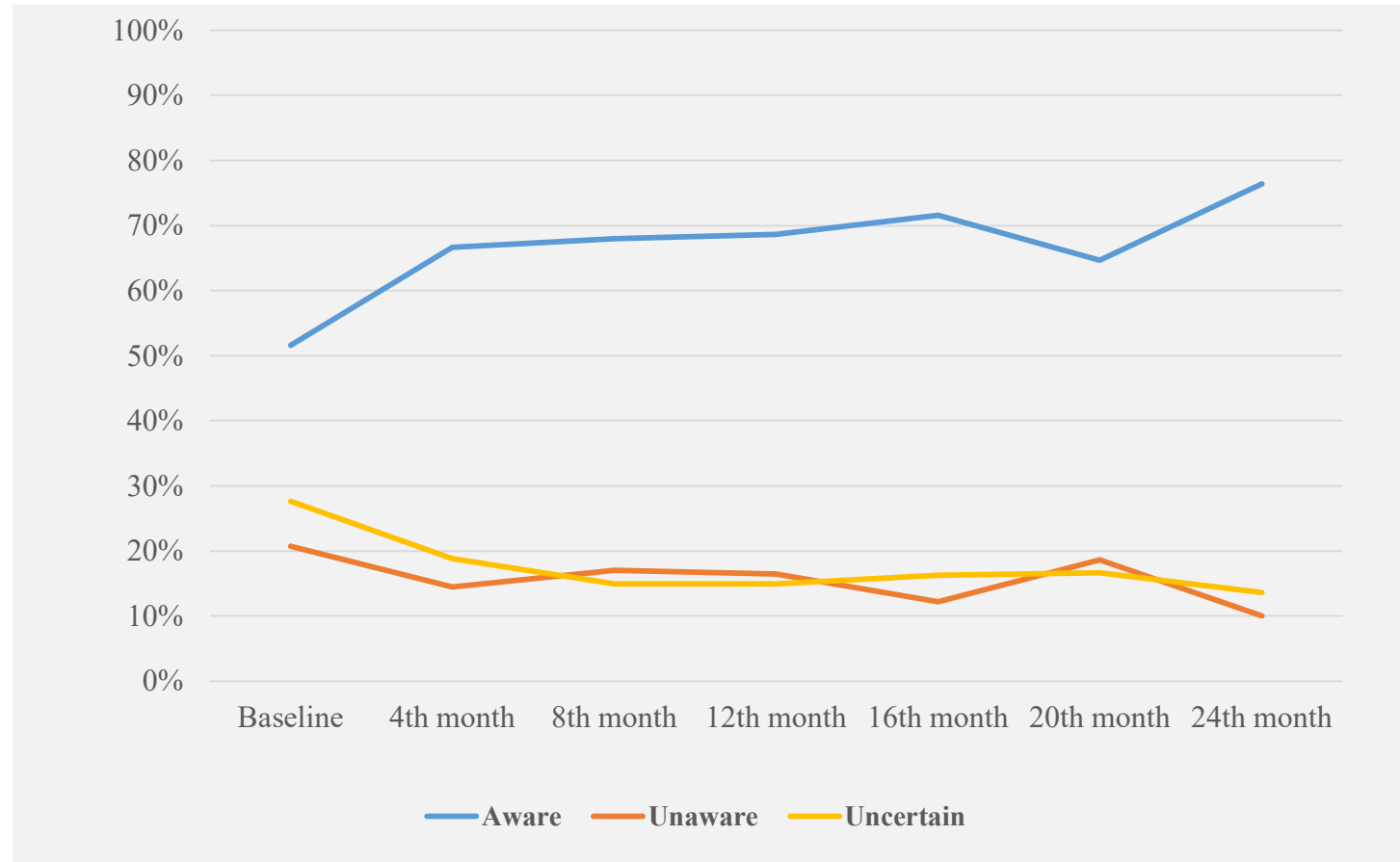


Ozdemir S et al (Cancer Medicine 2022). Prognostic Awareness and its Association with Health Outcomes in the Last Year of Life



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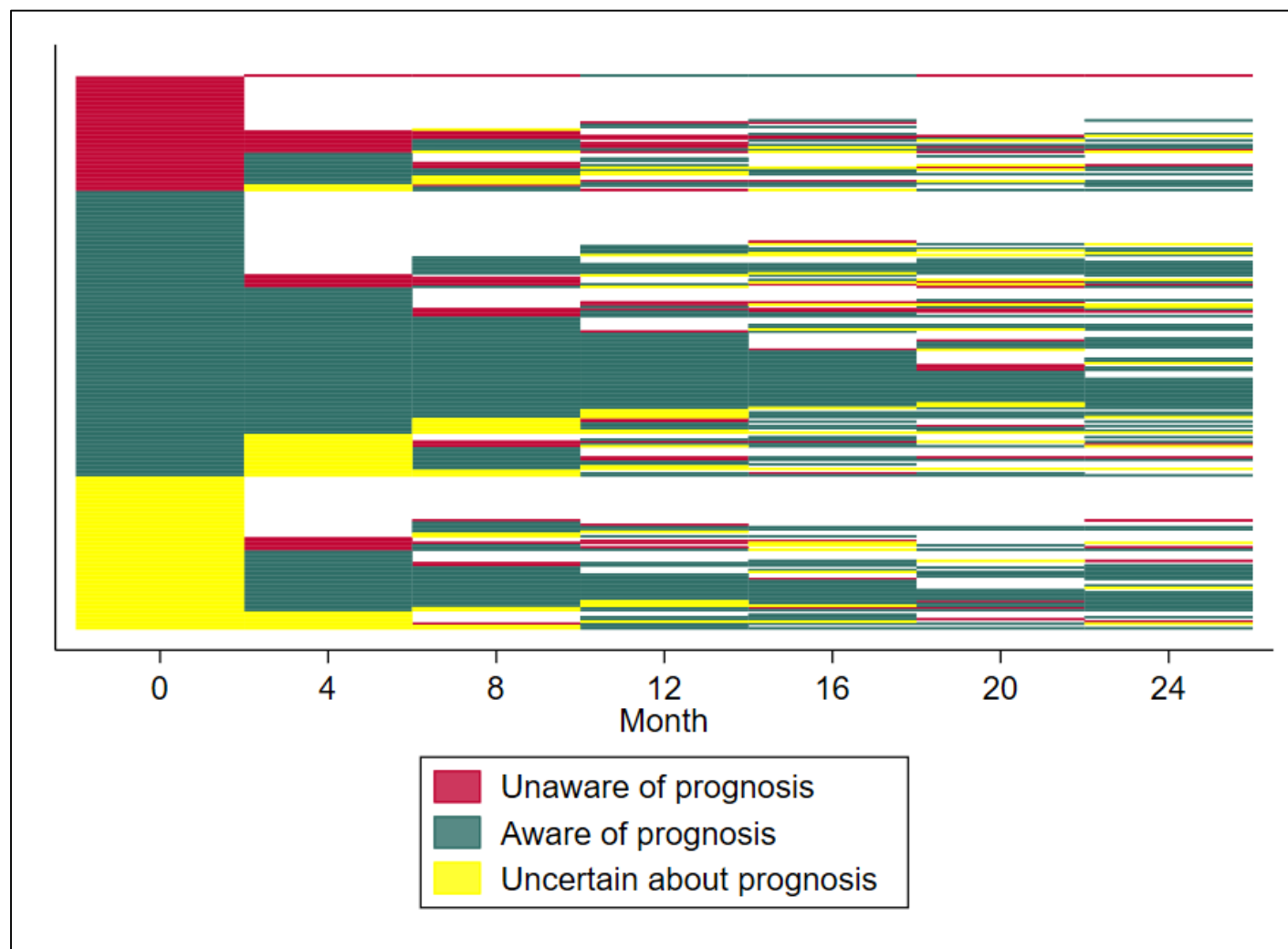
Heart failure: Prognostic awareness over 2 years (Baseline N=251)



The proportion of patients with prognostic awareness was 52% at baseline; increased to 76% at the 24th-month follow-up.

Ozdemir S et al (under review). A Prospective Cohort Study of Patients with Heart Failure: Prognostic Awareness and its Association with Patient-reported Outcomes

Heart failure: Prognostic awareness at the individual level over 2 years (Baseline N=251)



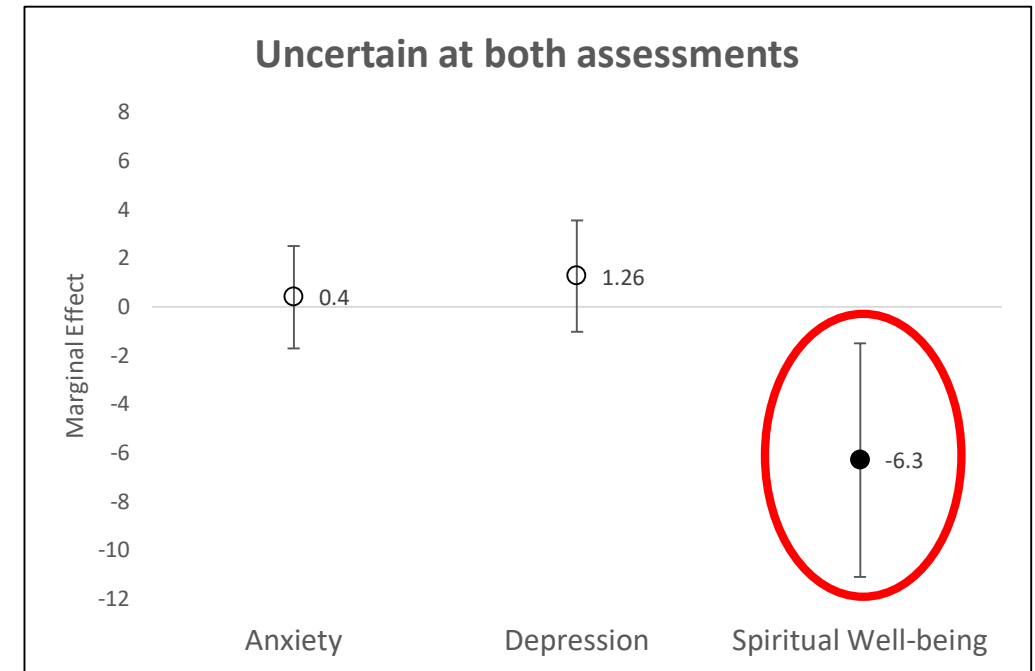
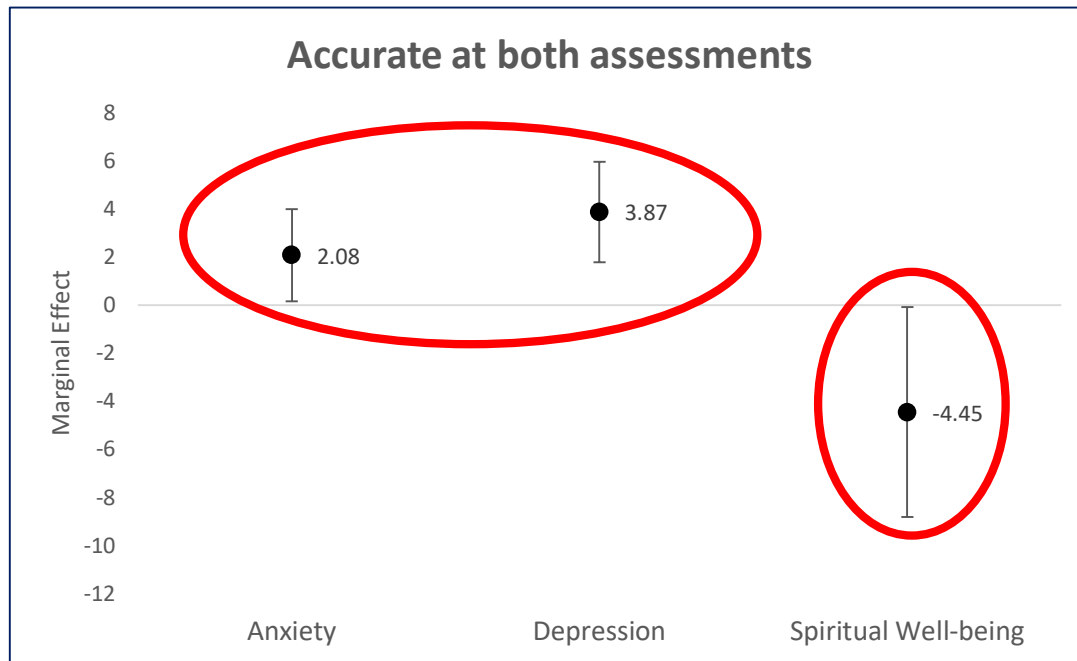
This graph shows the changes in patients' understanding of disease incurability at the individual level.

*Each line indicates one patient. White space indicates that the patient either died or dropped out of the study.

Is it good for patients to be aware of their prognosis?

Advanced cancer: Prognostic awareness and patient outcomes in the last year of life (N=176)

Reference level: Inaccurate awareness at both assessments



- Patients who reported accurate awareness at both assessments reported worsened anxiety, depression, and spiritual well-being.
- Patients who were uncertain at both assessments reported worsened spiritual well-being at the last assessment before death.

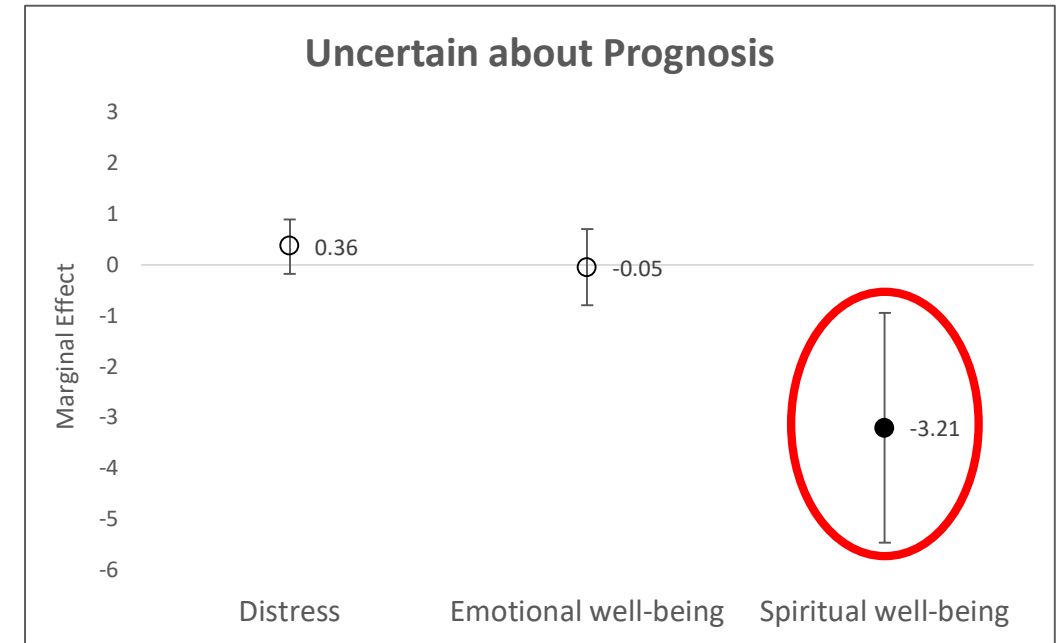
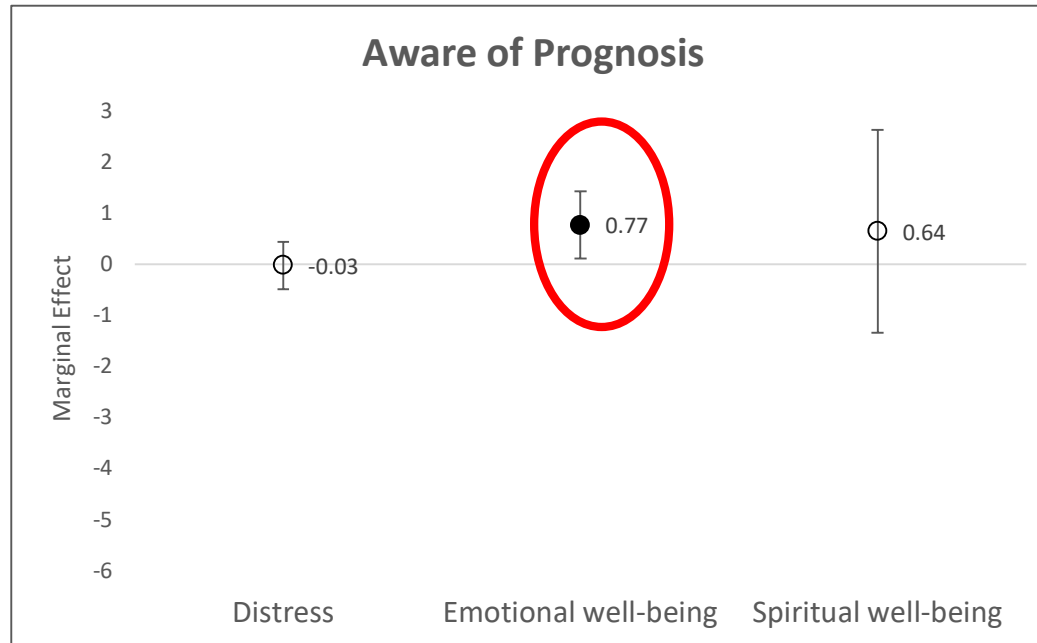
Ozdemir S et al (Cancer Medicine 2022). Prognostic Awareness and its Association with Health Outcomes in the Last Year of Life



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Heart failure: Prognostic awareness and patient outcomes over 2 years (Baseline N=251)

Reference level: Inaccurate prognostic awareness



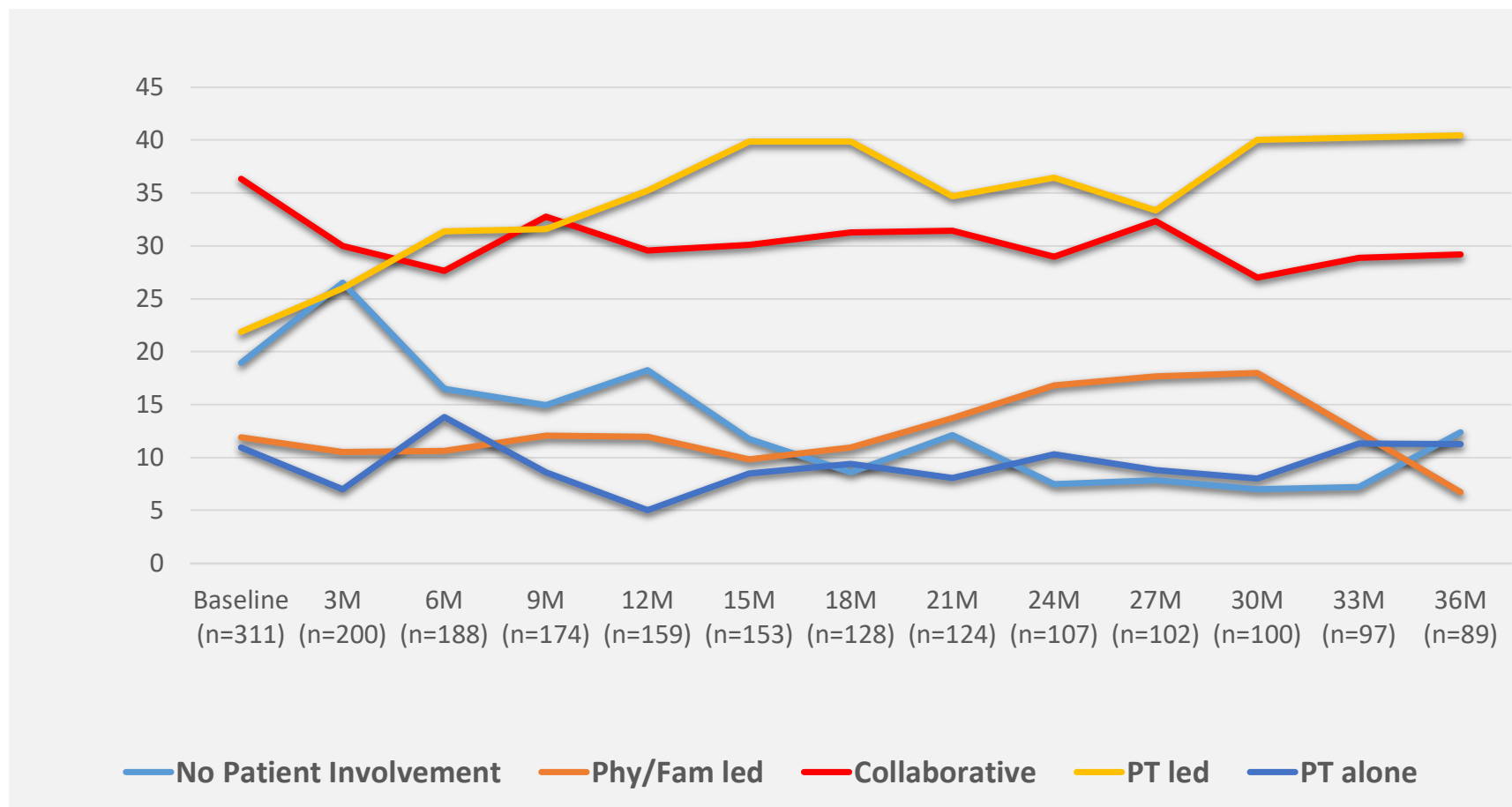
- Patients who were aware of their prognosis reported better emotional well-being.
- Patients who were uncertain about their prognosis reported worsened spiritual well-being.

Ozdemir S et al (under review). A Prospective Cohort Study of Patients with Heart Failure: Prognostic Awareness and its Association with Patient-reported Outcomes

Decision making:

Do patients want to be involved in decision-making?

Advanced Cancer: Preferred roles in decision-making over 3 years

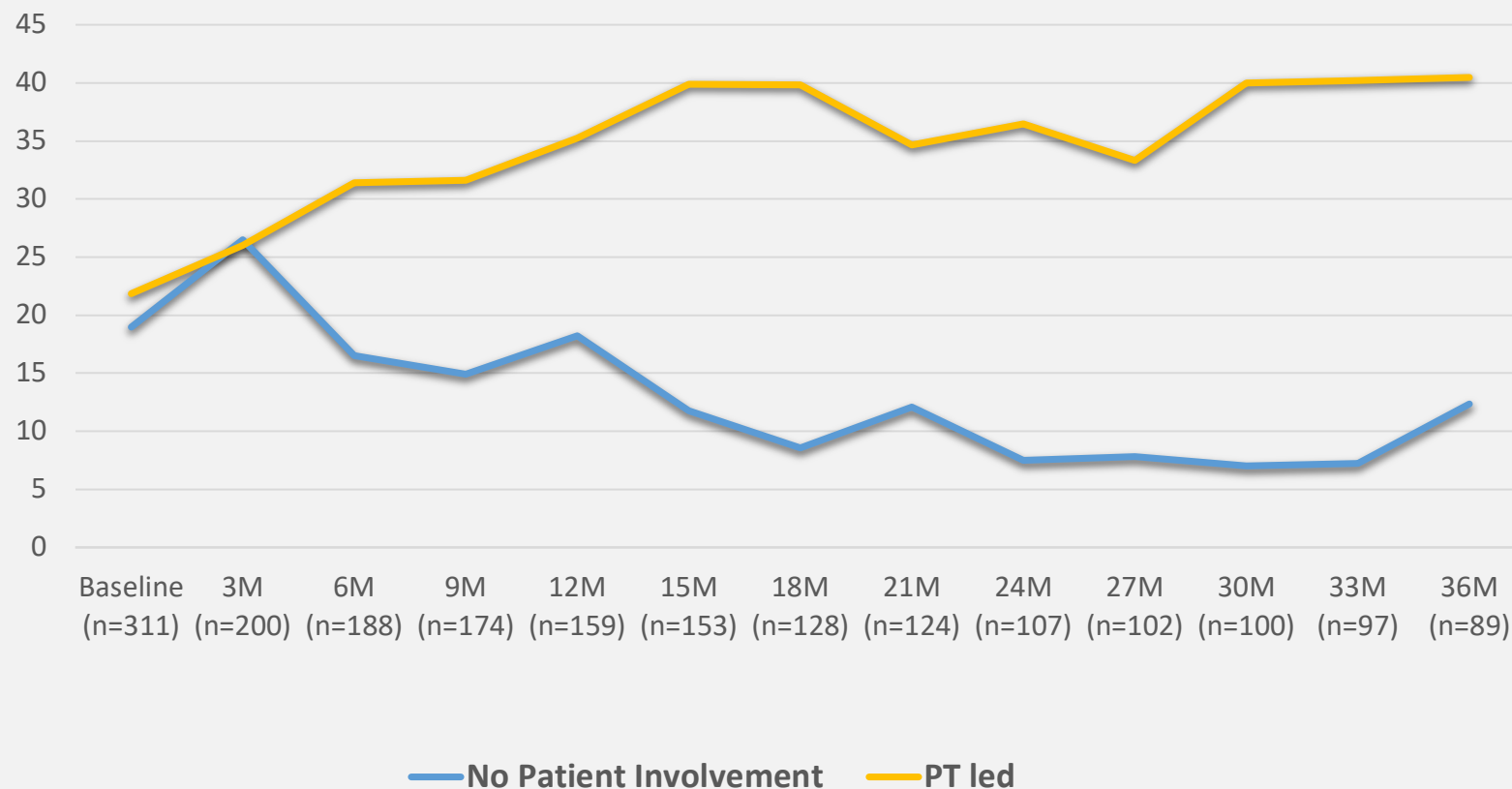


Level of Patient Involvement
(in increasing order)

- No involvement
- Physician/Family led
- Collaborative/Joint
- Patient led
- Patient alone

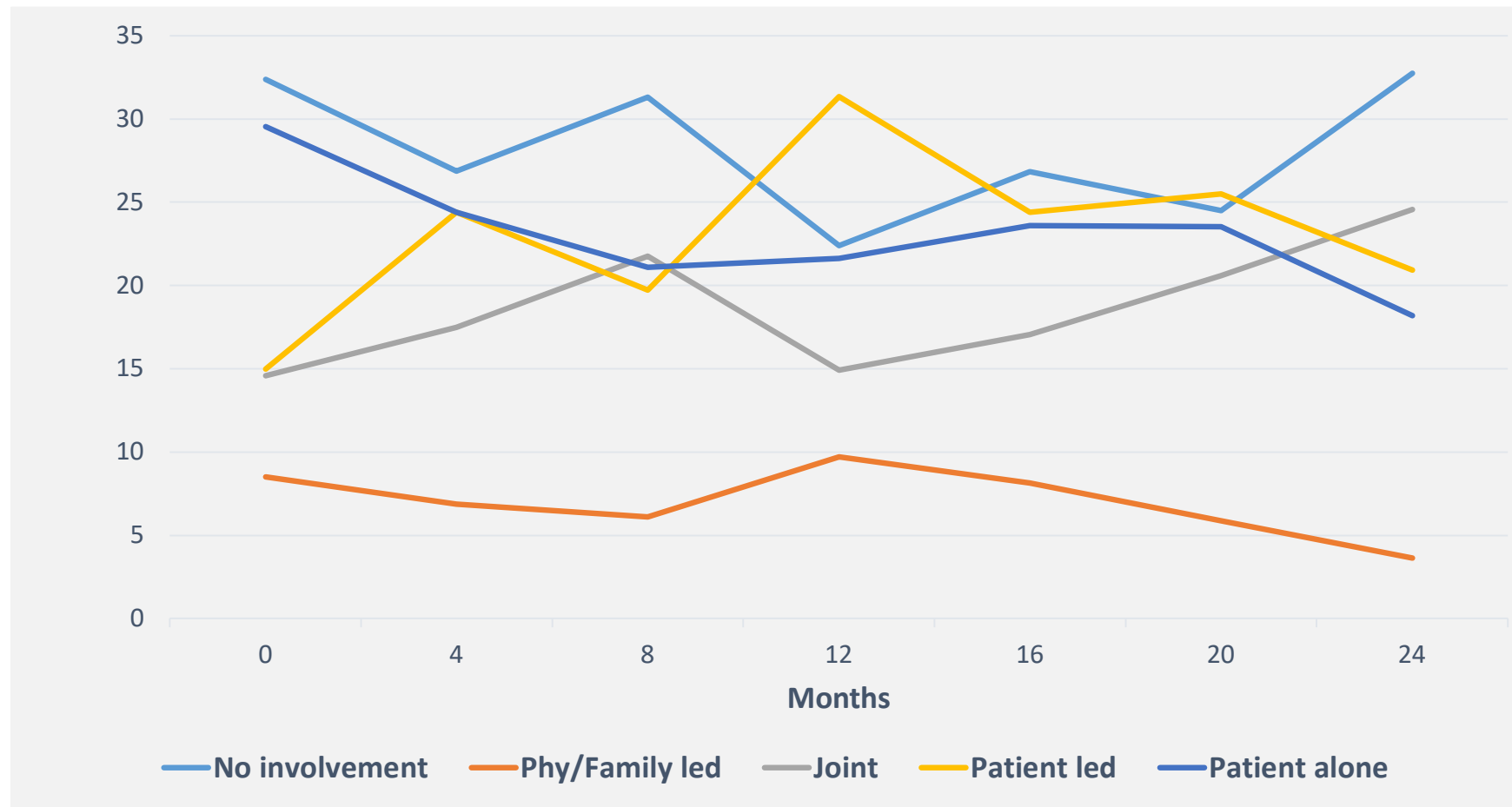
Ozdemir S et al (under review). A Prospective Cohort Study of Decision-Making Role Preferences of Patients with Advanced Cancer and Their Family Caregivers

Advanced Cancer: Preferred roles in decision-making over 3 years



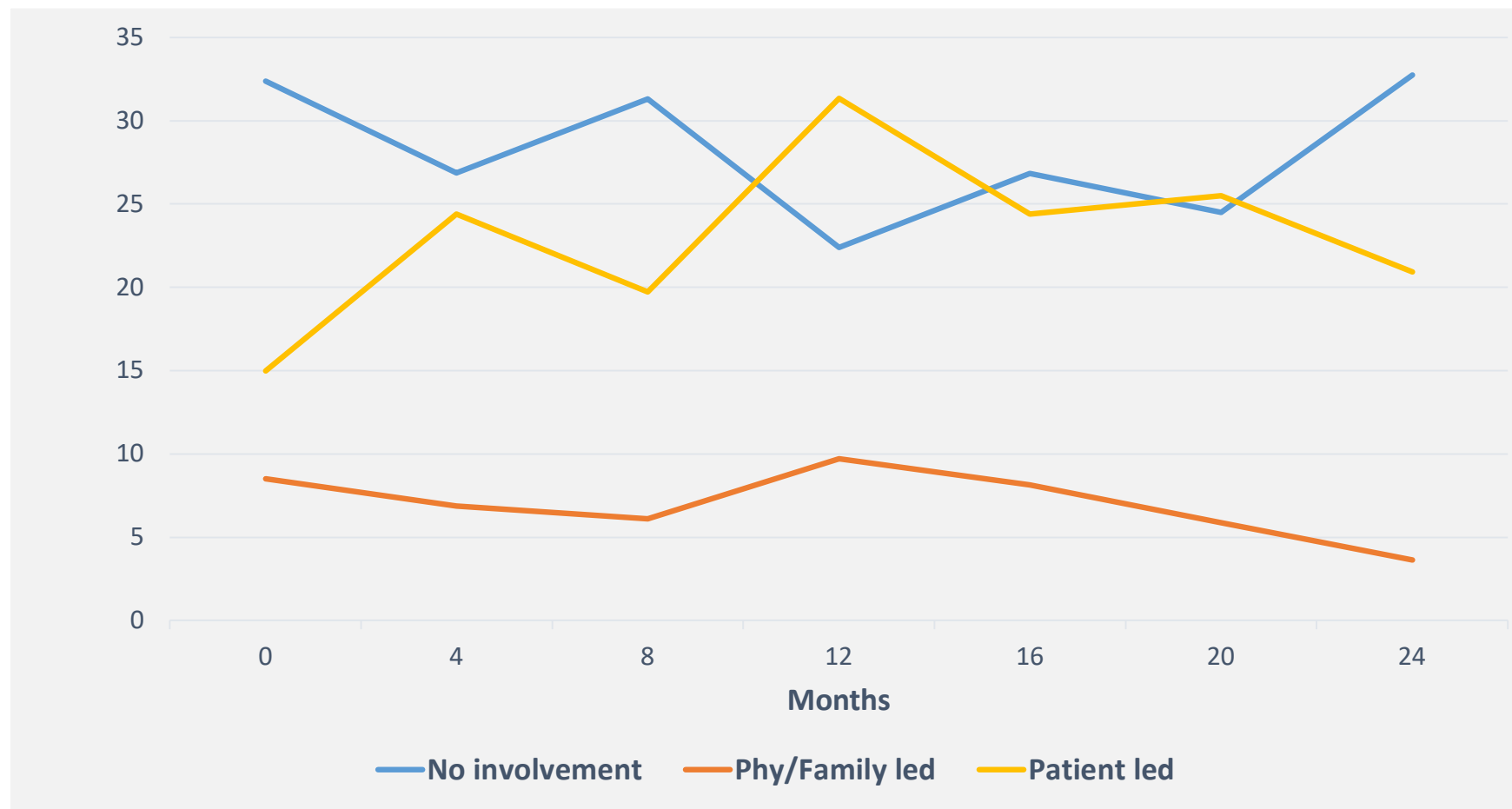
Patients preferred higher level of involvement in decision making over time.

Heart failure: Preferred roles in decision-making over 3 years



Ozdemir S et al (working paper). Preferences for Involvement in Decision-Making among Patients with Heart Failure: A longitudinal Study

Heart failure: Preferred roles in decision-making over 3 years



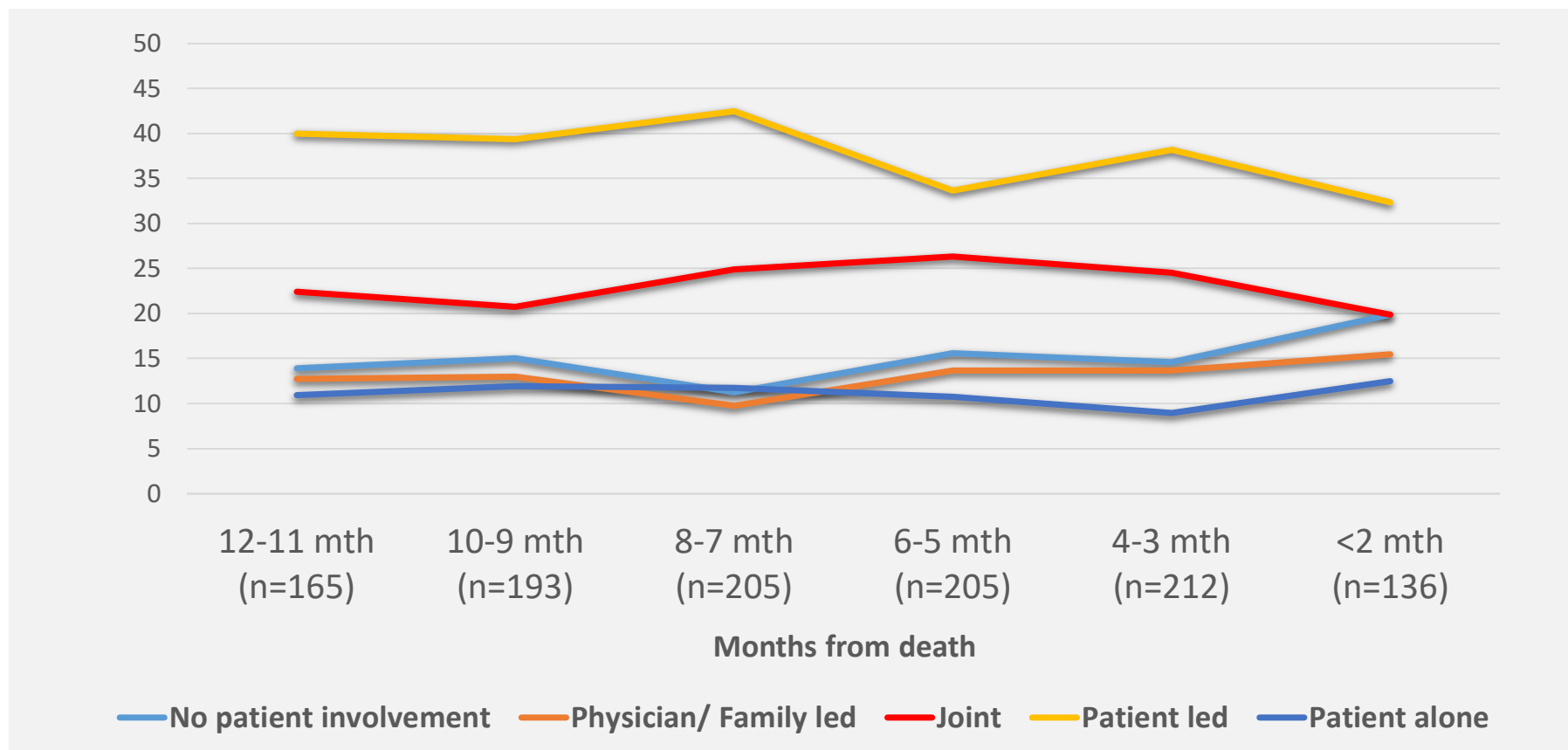
Patient preferences for the level of involvement in decision making did not change over 3 years.

Ozdemir S et al (working paper). Preferences for Involvement in Decision-Making among Patients with Heart Failure: A longitudinal Study

Decision making:

Are patients involved in decision-making?

Cancer: Distribution of perceived decision-making roles in the last year of life

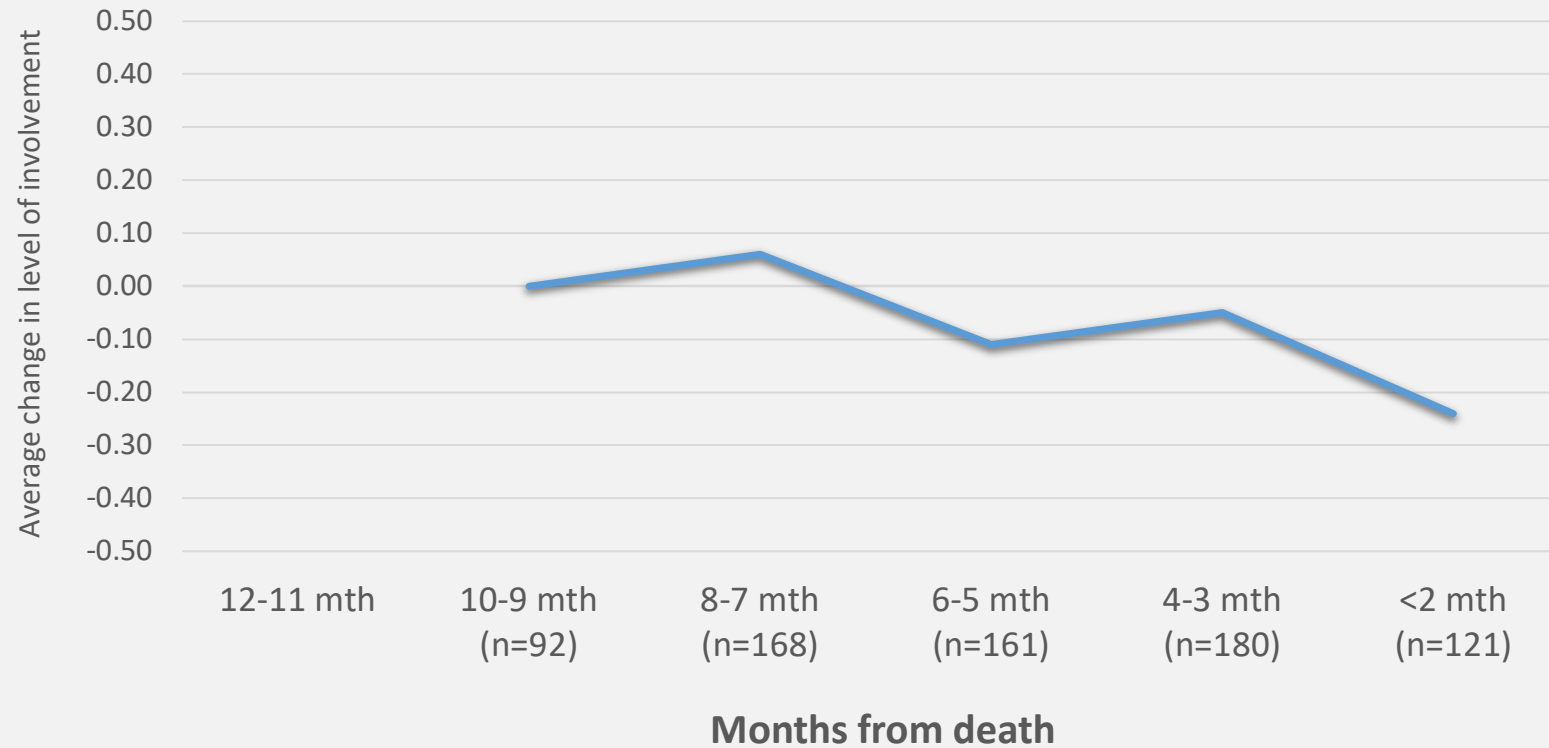


Patient level of involvement in decision-making decreased as death approached.



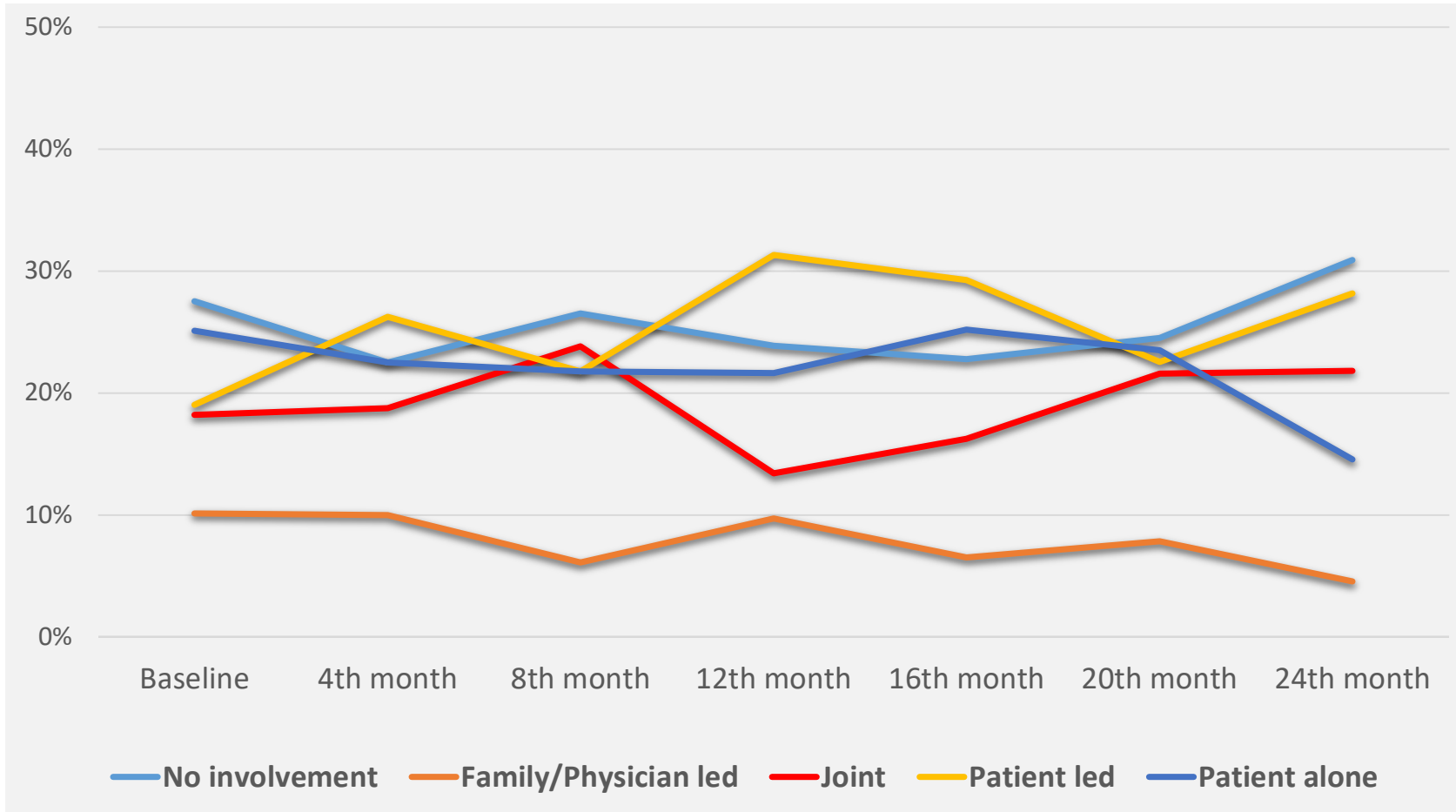
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Advanced cancer: Average change in perceived decision-making roles



*0 indicates no change; positive change indicates increasing level of patient involvement; negative change indicates decreasing level of patient involvement in decision-making.

Heart failure: Perceived roles in decision-making role over 2 years



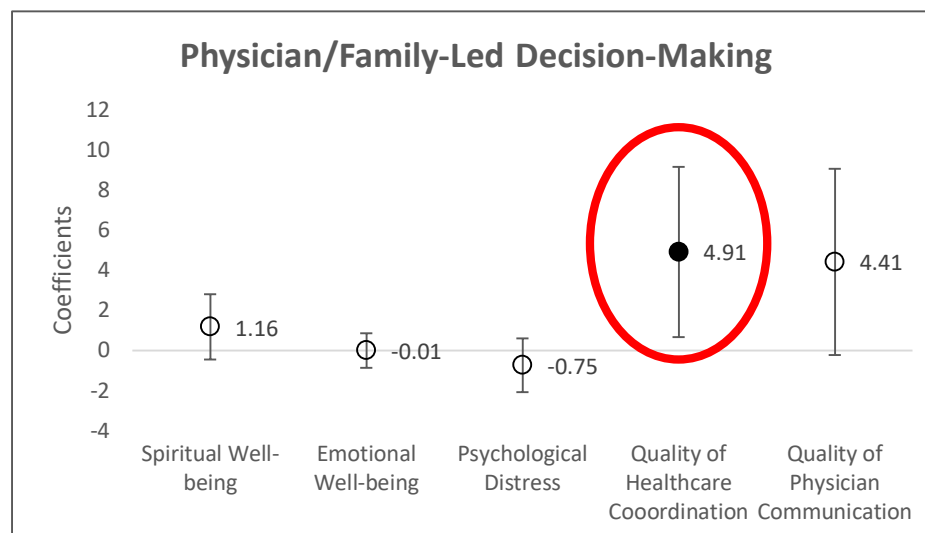
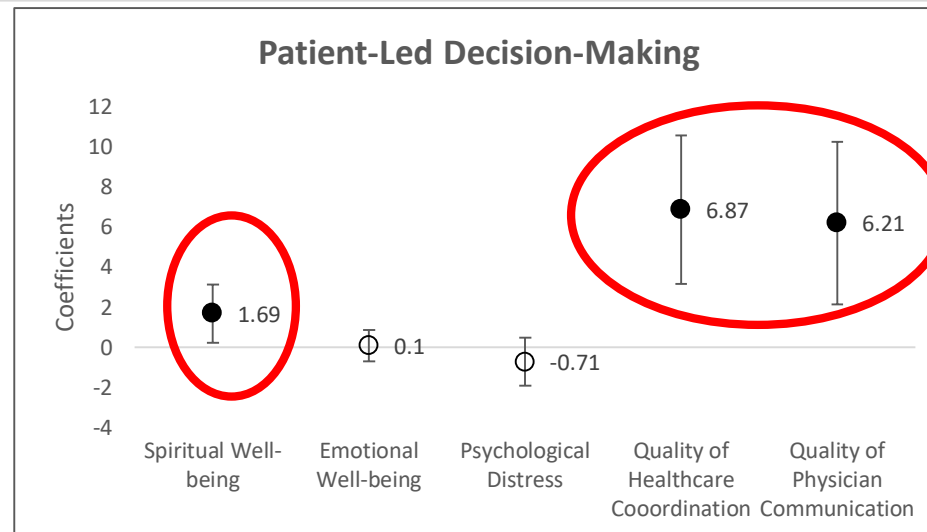
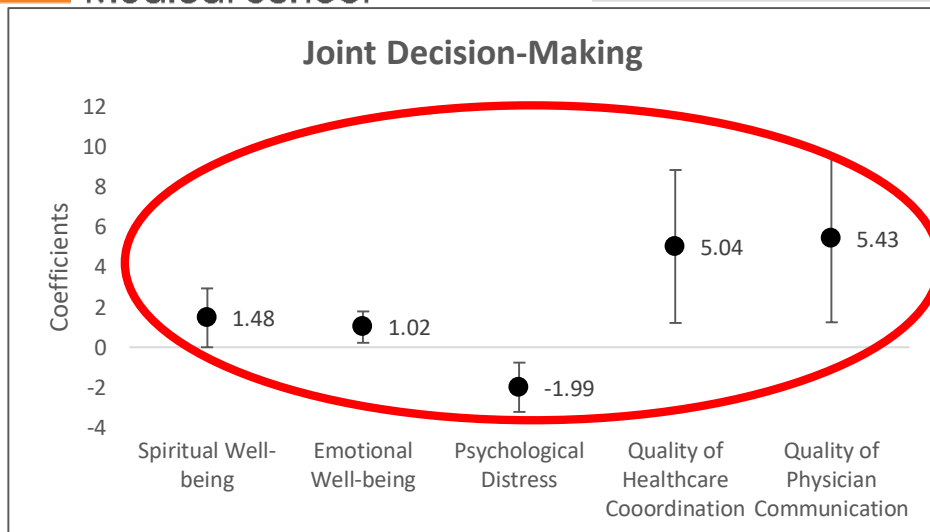
- The most common roles in decision-making at baseline were no patient involvement (28%) and patient-alone decision-making (25%).
- The level of patient involvement in decision-making roles did not change over 2 years.

Ozdemir S et al (under review). A prospective cohort study of patient's medical decision-making role and its association with patient characteristics and patient-reported outcomes among patients with heart failure

Decision making:

Is shared decision making good for the patients?

Advanced cancer: Perceived decision-making roles and patient outcomes in the last year of life

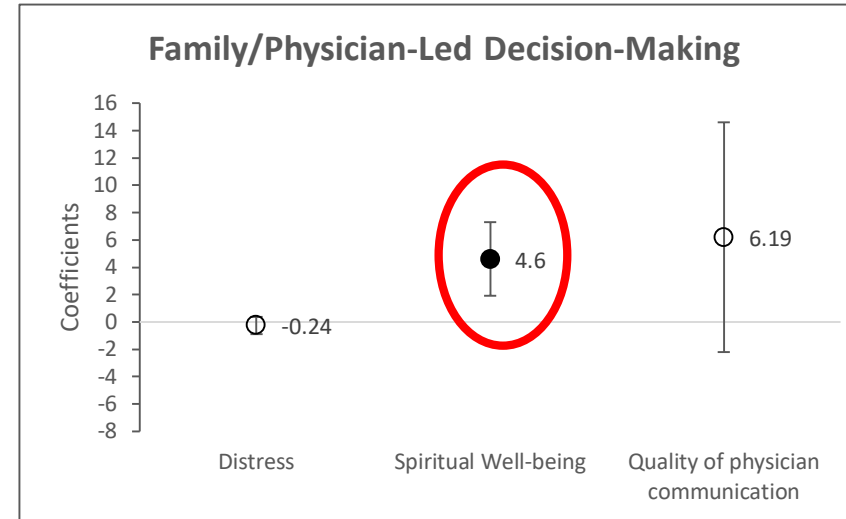


Reference level: No patient involvement

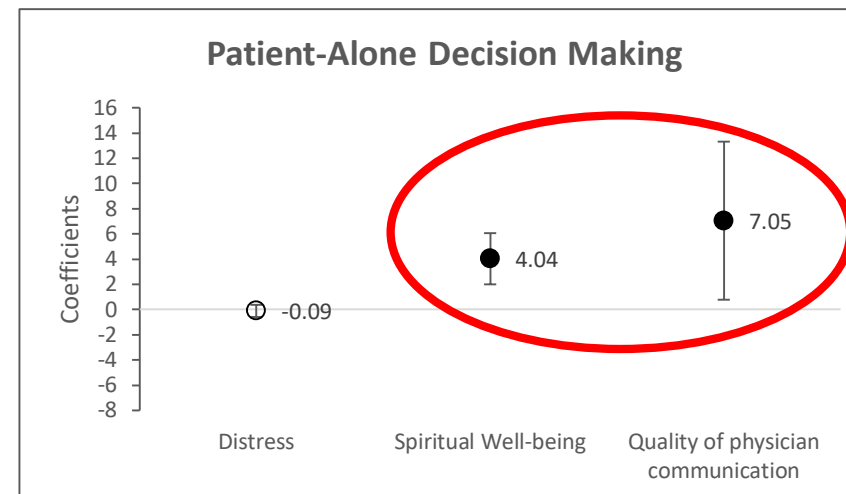
*No significant associations between patient-alone decision-making, quality of life, and perceived quality of care



Heart failure: Perceived decision-making roles and patient outcomes over 2 years



Reference
level: No
patient
involvement



Summary: What we learned

- Prognostic awareness
 - Prognostic awareness increased over time.
 - But still, quite a few patients (especially advanced cancer patients) either were inaccurate or uncertain.
 - Prognostic awareness was associated with worse outcomes for advanced cancer patients but better outcomes for heart failure patients.
 - Uncertainty about prognosis was more detrimental to both cancer and heart failure patients.

Summary: What we learned

- Decision making
 - There was variation in preferred and perceived roles in decision making.
 - Advanced cancer: Level of patient involvement decreased as death approached.
 - Heart failure: Level of patient involvement did not change over 2 years.
 - Patient-led, joint and family/physician-led decision-making were associated with better patient outcomes.
 - Patient-alone decision-making was associated with better patient outcomes for heart failure.

- Prognostic disclosure should be accompanied by interventions that help patients to cope with this information.
- Although shared decision making is not preferred for all patients, those who were involved in decision-making reported better well-being outcomes and better quality of care.
- Benefits of involvement in decision-making should be explained to patients and they should be encouraged to participate in decision making.

Thank you