Calling All Super Heroes

Palliative Care in HCT: Benefits, Challenges and the Patient Experience

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Saturday November 10th

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Disclosures

The following faculty and planning committee staff have no financial disclosures:

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Learning Objectives

- ✓ Discover patient and caregiver palliative and supportive care needs from diagnosis through transplant and beyond
- ✓ Synthesize the current science regarding the benefits of palliative care integration
- ✓ Evaluate current barriers to palliative care integration and
- ✓ Assess potential solutions to improve palliative care integration

Palliative Care Integration in HCT

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MASSACHUSETTS GENERAL HOSPITAL
CANCER CENTER

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CANCER OUTCOMES RESEARCH

Outline

- Unmet palliative care needs in patients with hematologic malignancies and those undergoing HCT
- Barriers to palliative care integration
- A model of successful palliative care integration in patients with hematologic malignancies undergoing HCT
- Where do we go from here?

Unmet Palliative Care Needs

- Patients with hematologic malignancies have substantial unmet palliative care needs throughout their illness trajectory
  - Psychological trauma of unexpected diagnosis
  - Intensive therapies leading to significant symptom burden
  - Unmet EOL care needs
  - Survivors struggle with long-term complications

Unmet Palliative Care Needs

Despite substantial unmet needs, palliative care is rarely utilized for patients with hematologic malignancies

Why?

Illness Specific Barriers

- Hematologic malignancies are just different:
  - Prognostic uncertainty
  - Absence of clear transition between curative phase and palliative phase of treatment
  - Rapid and unpredictable trajectory of decline at the EOL
  - Complications at the EOL are also different:
    - Need for blood product support
    - Infectious complications
    - Bleeding complications

El-Jawahri, Curr. Hematol 2016

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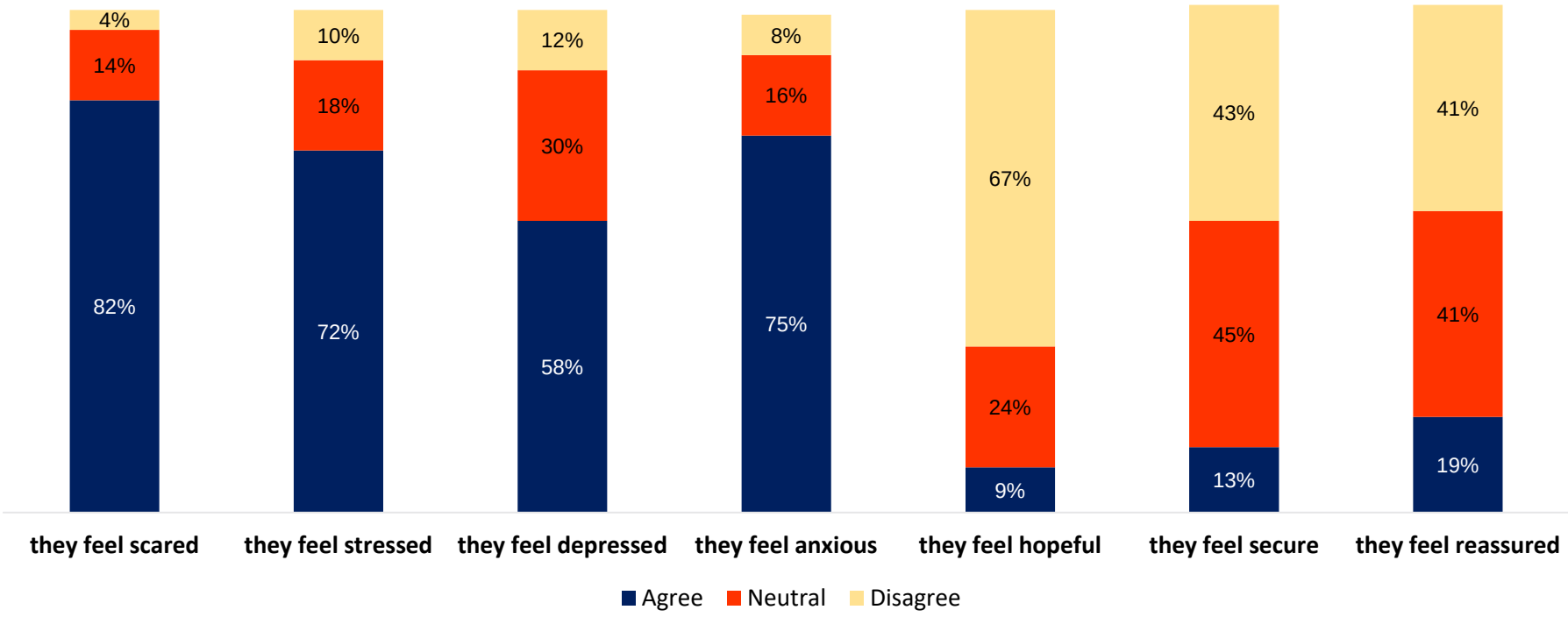
Cultural Barriers

- Misperceptions equating palliative care with just EOL care
- Lack of exposure to palliative care – mistrust
- Palliative care services have not been exposed enough to this population

LeBlanc, ASH Educ Program 2015
El-Jawahri, JOP 2017

Cultural Barriers

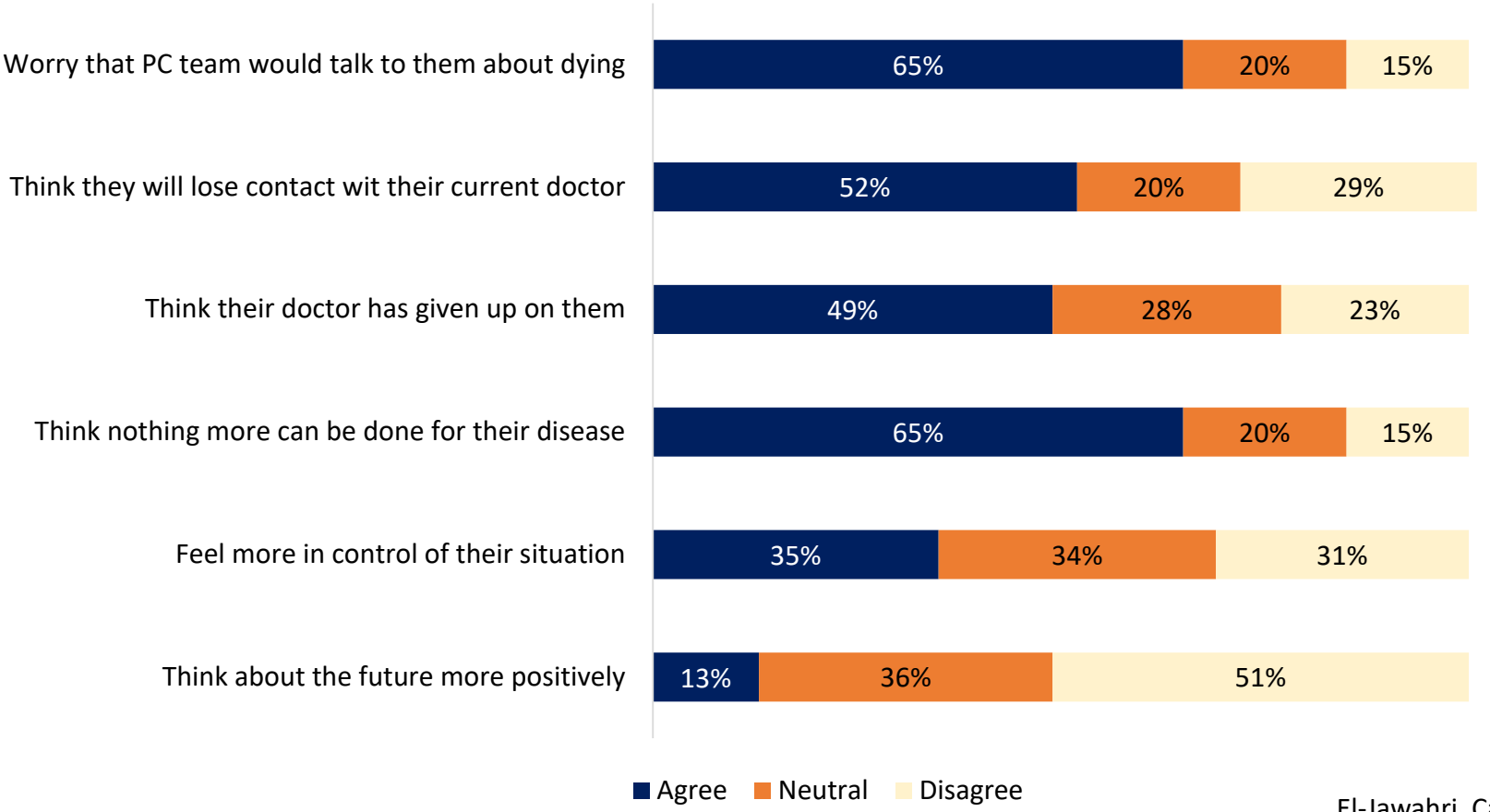
Physician's perception: "When patients hear the term palliative care":



El-Jawahri, Cancer 2018

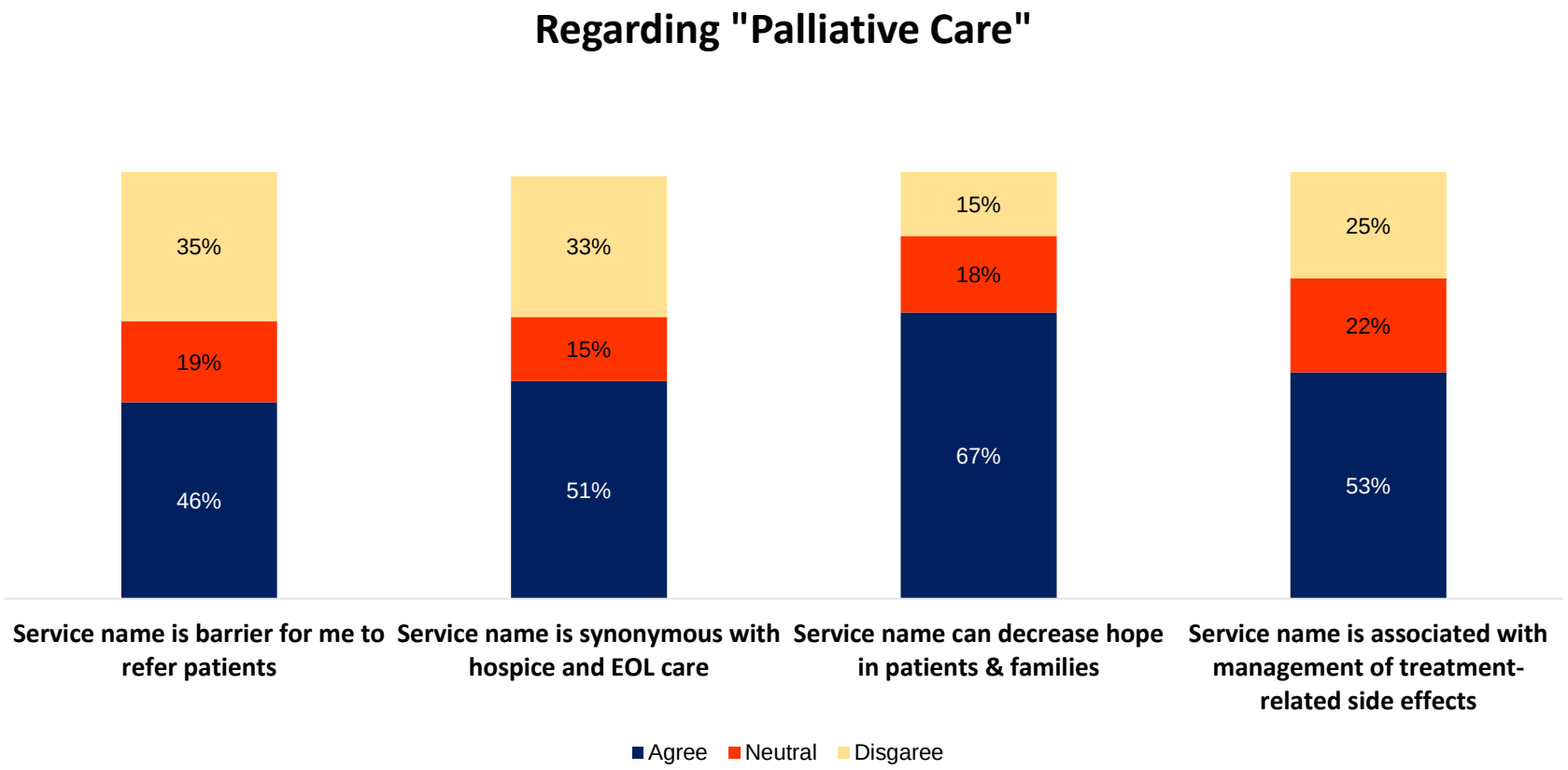
Cultural Barriers

If a palliative care referral is suggested for a patient, they might:



El-Jawahri, Cancer 2018

Cultural Barriers



El-Jawahri, Cancer 2018

System-Based Barriers

- EOL care delivery models → not developed for hematologic malignancies
- Difficulty managing blood product support at the EOL
- Challenges of addressing infectious complications at the EOL
- How to manage GVHD in hospice?
- Lack of understanding of what death looks like for a heme-malignancy patients
- Lack of preparation for family

El-Jawahri, Curr. Hematol 2016
El-Jawahri, JOP 2017

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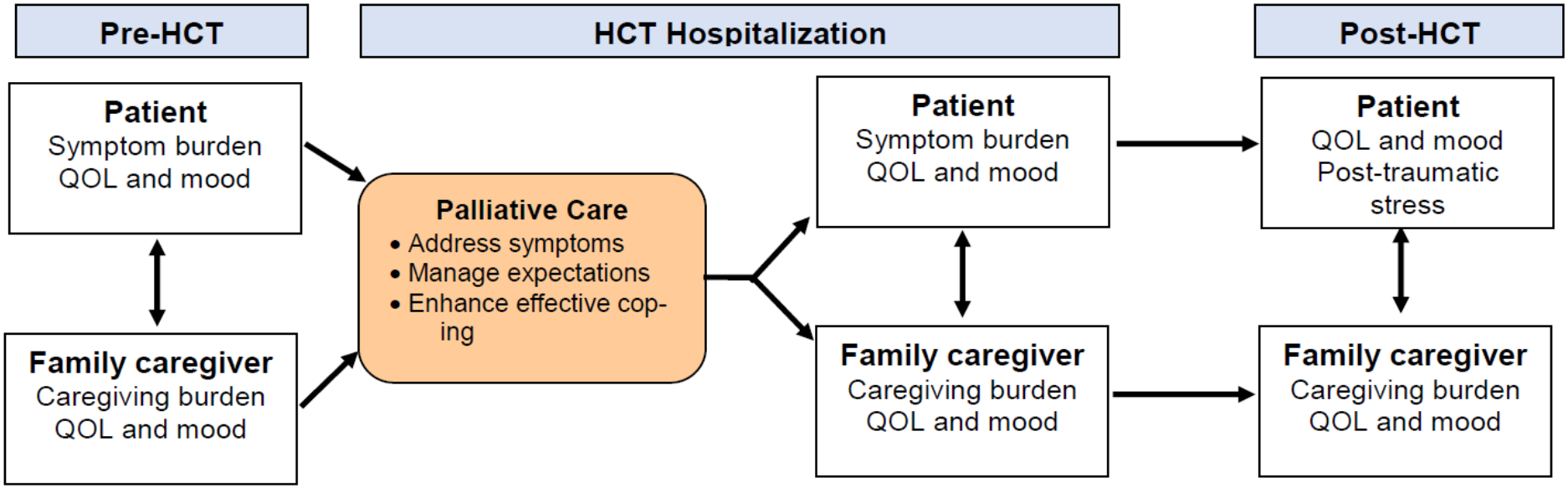
Rationale for Palliative Care in HCT Model

- Symptom management needed during HCT
- HCT patients rarely utilizes palliative care services
- Opportunity to build trust: palliative care & hematologic malignancies
- Population-specific palliative care & oncology care model

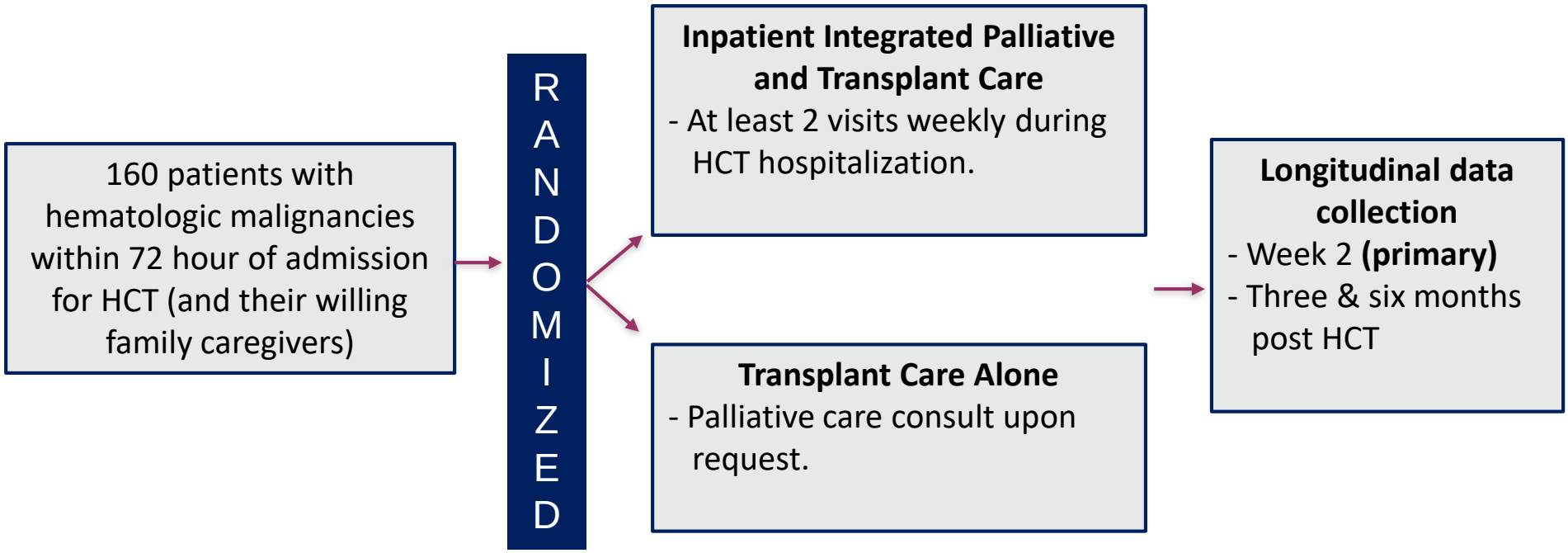
SHIELD: Conceptual Model

Conceptual Model:

Figure 1

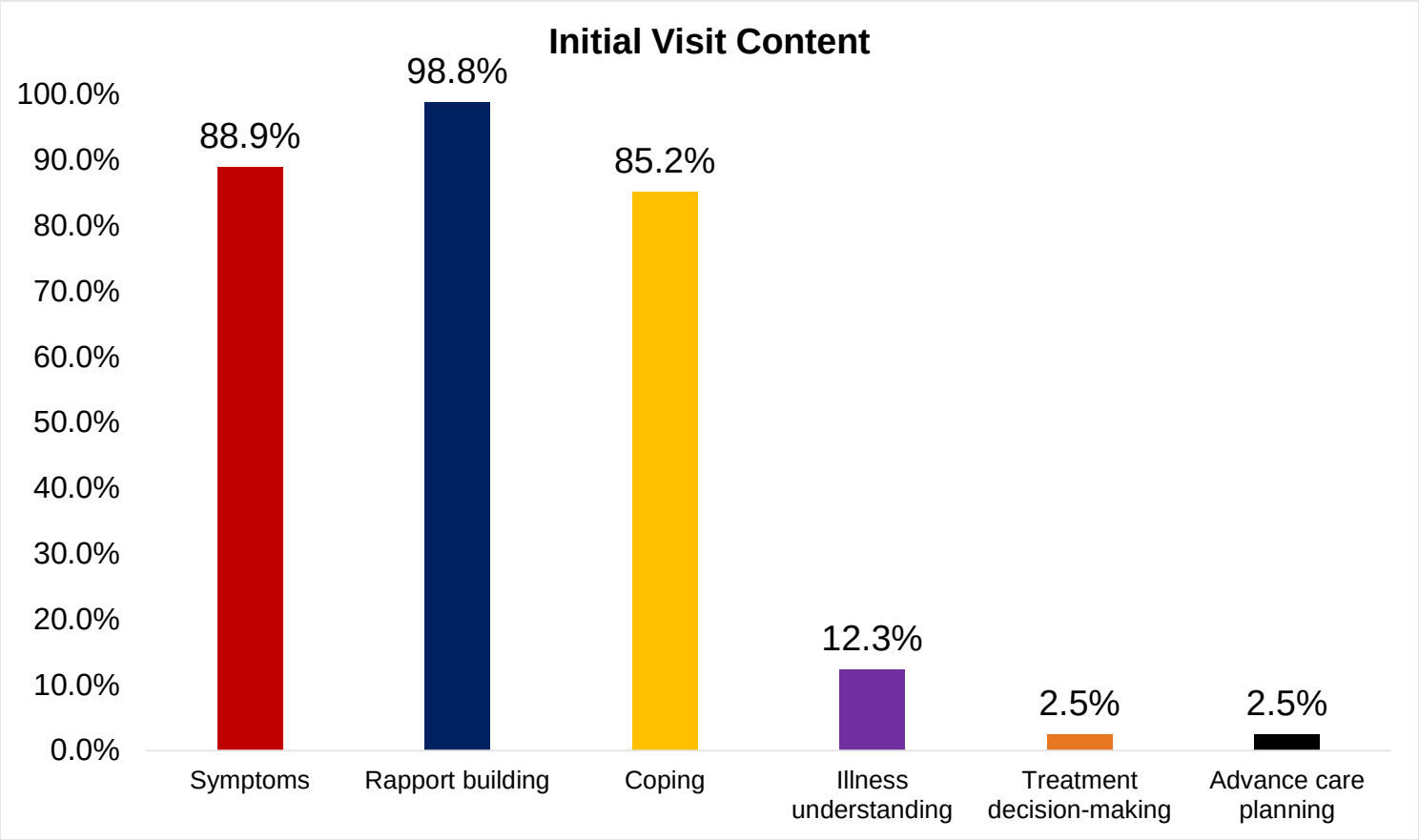


Study Design

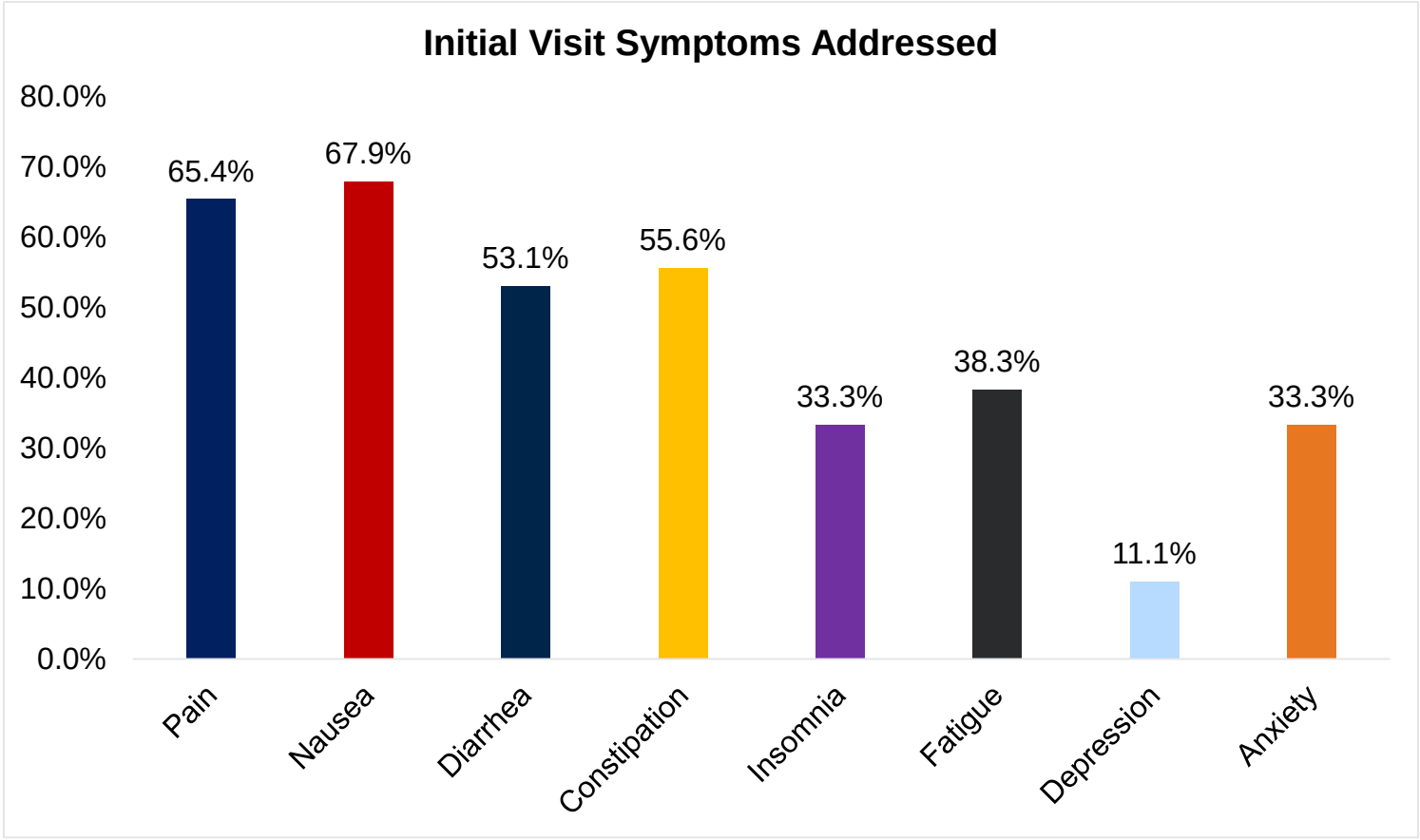


El-Jawahri JAMA 316(20) 2016

Palliative Care Intervention



Palliative Care Intervention



Patient Week-2 Outcomes

Week-2 Outcomes	Adjusted Mean Difference	95% CI	P- Value
FACT – BMT	7.73	1.27 to 14.19	**0.019**
FACT – Fatigue	3.88	0.21 to 7.54	**0.038**
ESAS – Symptom Burden	-6.26	-11.46 to -1.05	**0.019**
HADS – Depression symptoms	-1.74	-3.01 to -0.47	**0.008**
HADS – Anxiety symptoms	-2.26	-3.22 to -1.29	**<0.001**
PHQ-9 – Depression	-1.28	-2.82 to 0.27	0.104

El-Jawahri JAMA 316(20) 2016

Patient 3 Month Outcomes

3 Month Outcomes	Adjusted Mean Difference	95% CI	P- Value
FACT – BMT	5.34	0.04 to 10.65	**0.048**
FACT – Fatigue	2.00	-1.08 to 5.09	0.202
ESAS – Symptom Burden	-2.44	-6.29 to 1.41	0.212
HADS – Depression symptoms	-1.70	-2.75 to -0.65	**0.002**
HADS – Anxiety symptoms	-0.76	-1.73 to 0.23	0.130
PHQ-9 – Depression	-2.12	-3.42 to -0.81	**0.002**
PCL – PTSD Symptoms	-4.35	-7.12 to -1.58	**0.002**

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Patient 6 Month Outcomes

6 Month Outcomes	Adjusted Mean Difference	95% CI	P- Value
FACT – BMT	2.72	-2.96 to 8.39	0.346
FACT – Fatigue	0.10	-3.38 to 3.58	.957
HADS – Depression symptoms	-1.21	-2.26 to -0.16	**0.024**
HADS – Anxiety symptoms	-0.61	-1.69 to 0.47	0.267
PHQ-9 – Depression	-1.63	-3.08 to -0.19	**0.027**
PCL – PTSD Symptoms	-4.02	-7.18 to -0.86	**0.013**

El-Jawahri, JCO 2017, in press

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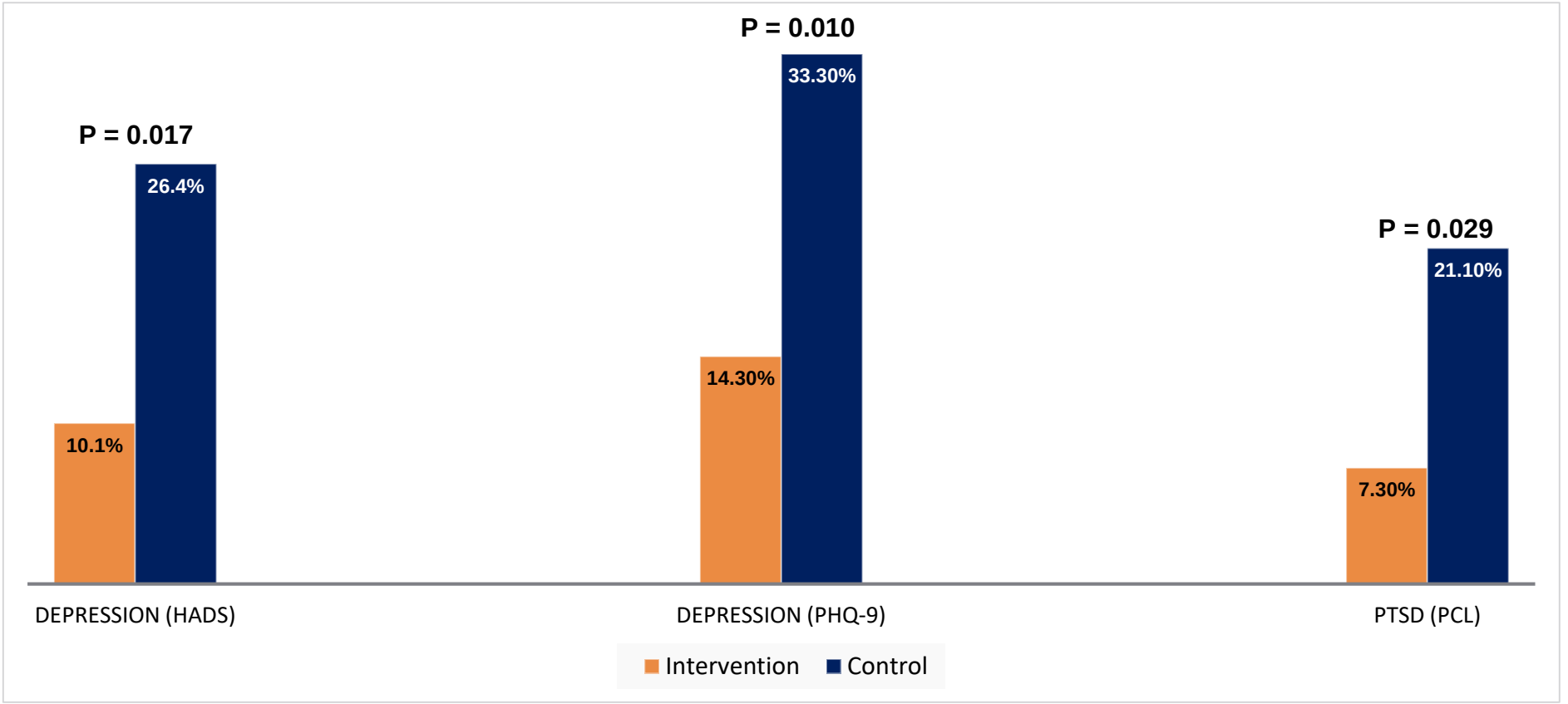
Psychological Distress Six Months



El-Jawahri, JCO 2017, in press

Caregiver Outcomes

2-week Caregiver Outcomes	Adjusted mean difference	95% CI	P-value
HADS-Depression	-1.65	-3.01 to -0.29	**0.018**
HADS-Anxiety	-0.14	-1.56 to 1.27	0.84
QOL	3.38	-1.59 to 8.35	0.180

- **Improvement in two domains of QOL**
  - **Coping:** adjusted mean difference = 1.01, **P = 0.009**
  - **Administrative/finances:** adjusted mean difference = 0.67, **P = 0.029**

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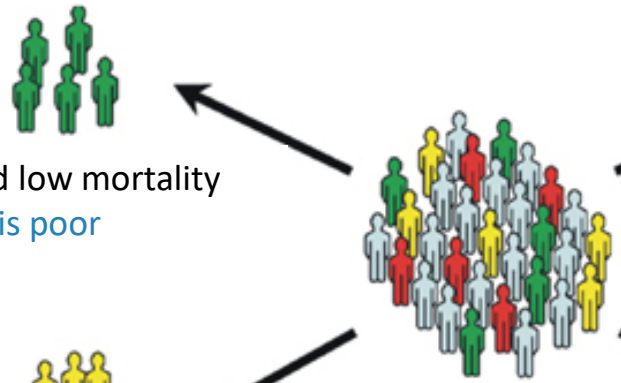
This is not one-size-fits all



Patients with hematologic malignancies

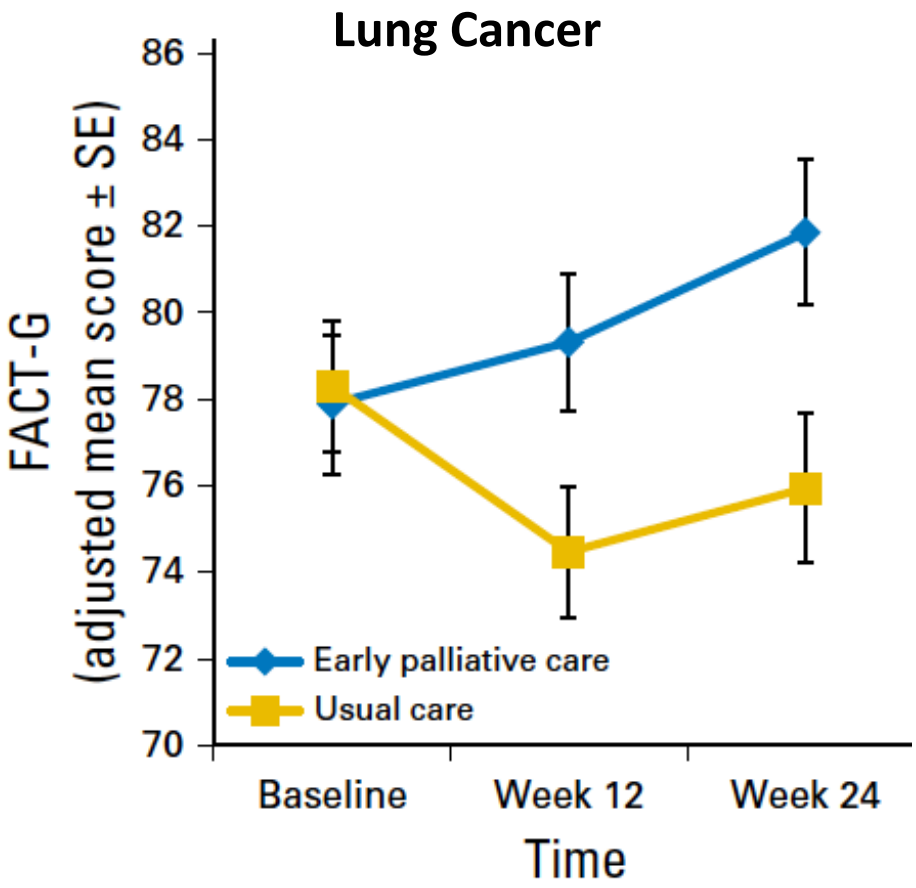
Low symptom burden and low mortality
PC when prognosis poor

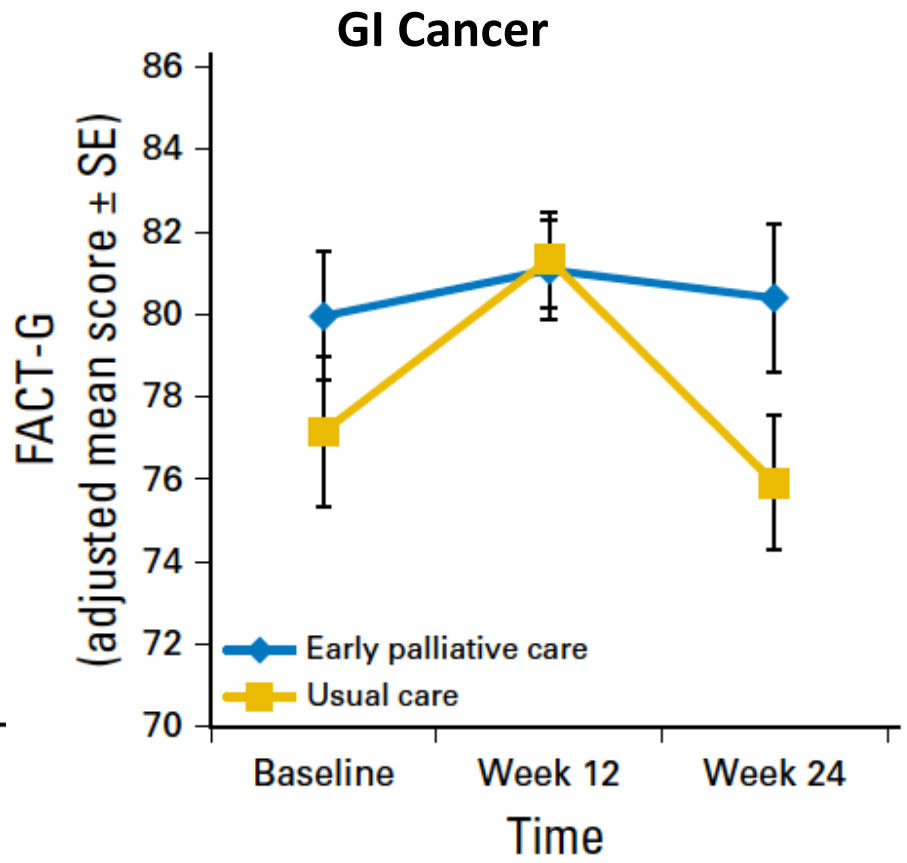
High symptom burden and mortality
Early longitudinal PC

Moderate symptom burden and mortality
Early intermittent PC

Prolonged periods with low symptom burden
Identify triggers for PC (i.e. hospitalization)

MGH Integrate PC Trial





Temel, JCO 2017

Where Do We Go from here?

- Further need for proof-of-principal trials in novel populations of patients with hematologic malignancies
- Developing palliative care models that are tailored to the need of patients and their families
- Understanding mechanism of the benefits of palliative care
- Who benefits the most from early palliative care integration?
- Developing less resource-intensive models/ telemedicine
- Developing primary palliative care interventions