Supportive Care
Reality vs. Perception

Jessica MacIntyre, ARNP, NP-C, AOCNP®

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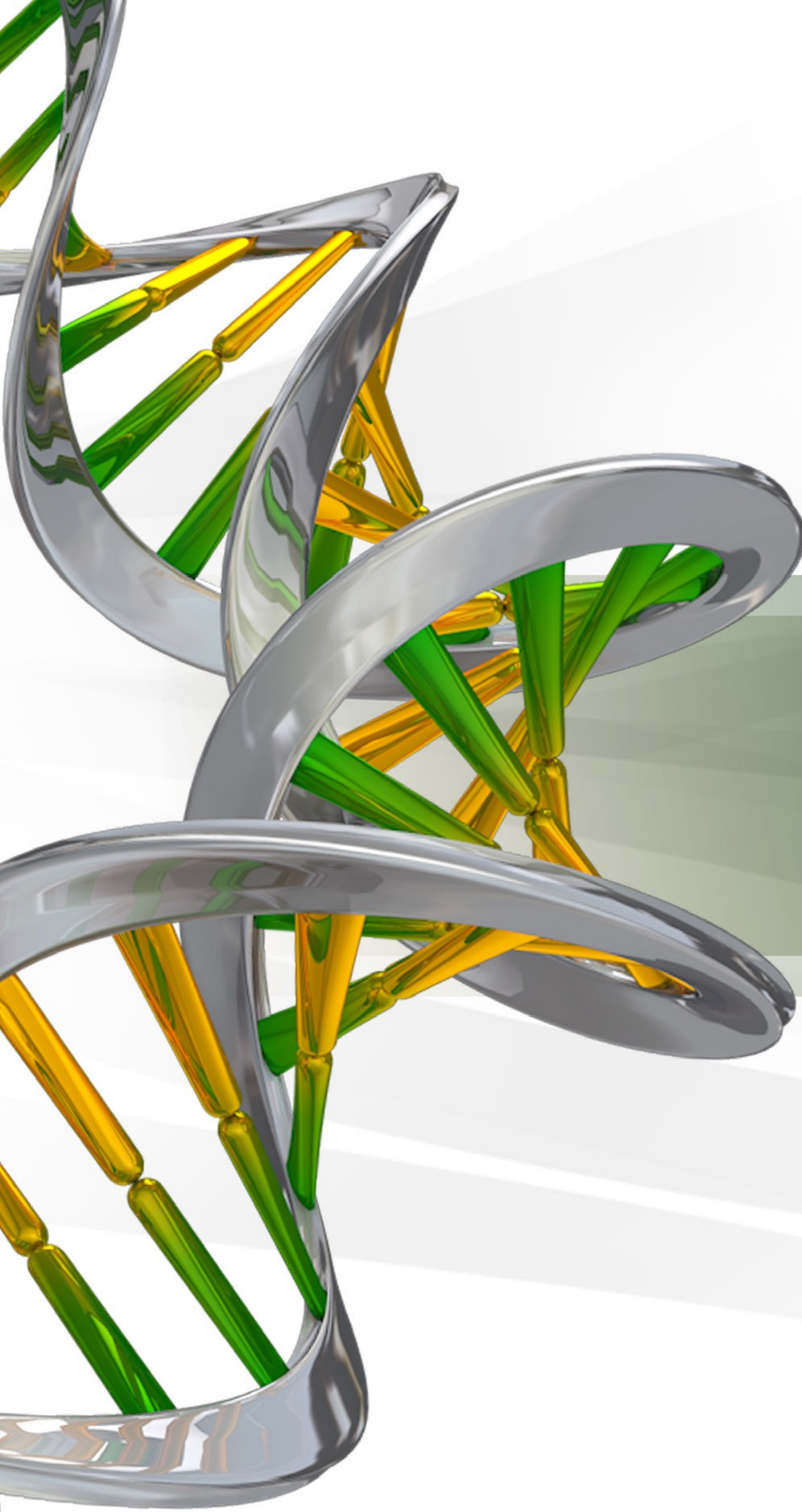

Thanks to Adrienne Vazquez!
NP Council of Miami-Dade

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Disclosures

Genentech Speakers Bureau
Celegene Speakers Bureau

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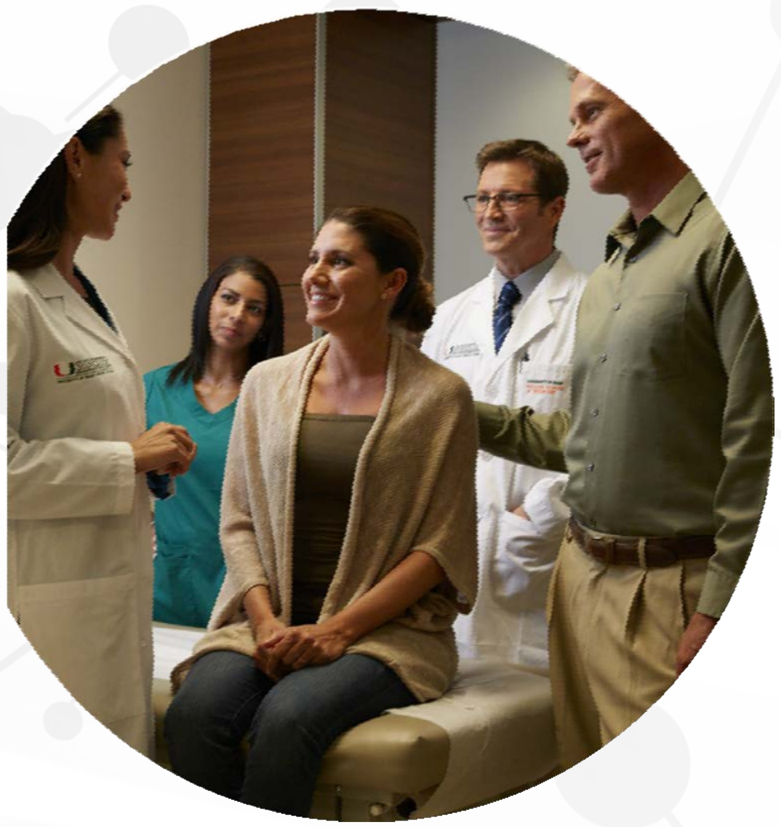
Objectives

- Define supportive care
- Discuss areas that surround supportive care
- Review supportive care updates from ASCO 2017 and the 2017 ASCO Palliative and Supportive Care Oncology Symposium.



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How do you define supportive care?

Does how you define it effect your patient(s)/families perspective?

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Matter of perspective?

Point of View

Matter of perspective?

Why a difference in provider perspective?

- Limited training/knowledge (medical/nursing education)
- Knowledge from mentor(s)
- Patient population (i.e. breast vs. pancreatic cancer)

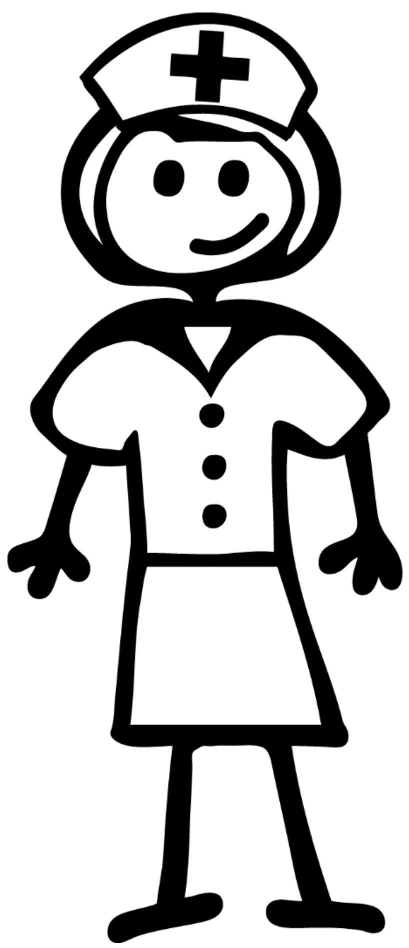
Why a difference in perspective?

Lack of familiarity with the term

Negative associations with the term

Prior experiences with friends and loved ones

Referrals late in disease course= end of life



Less favorable impression
Lower perceived need for these services

Maciasz et. al. (2013). Support Care Cancer. Online suppl DOI10.1007/s00520-013-1919-z

Why a difference in perspective?

COMMUNICATION!

Providers should be aware that the manner in which they communicate information about palliative care affects perceptions of its meaning and decision making about receiving such care.

http://www.cmaj.ca/content/cmaj/188/10/E217.full.pdf

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What’s in a Name?

- **Supportive care vs. Palliative care**

-Synonomous with palliative care.
- Termed also “best supportive care.”

-Recent survey of 1000 American adults indicated 24 % were familiar with the term palliative care and 86% were familiar with the term hospice care.[1]

-Providers have difficulty with the name “palliative care.”
-61% of oncology specialists agreed that the service name can decrease hope in patients and families vs 15% for supportive care[2]
-Resulted in delays in referrals

1. Available: http:\\syndication.national journal.com/communications/NationalJournalRegenceToplines .pdf (accessed 2015 Sept. 23).
2.Hui et. al. The Oncologist 2015;20:1326-1332

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What's in Name?

- Supportive care vs. Palliative care.

Table 1. Palliative care and supportive care referral by oncology specialty

Survey statement	Hematologic oncology, *n* (%)			Solid tumor oncology, *n* (%)			
	Faculty	MLP	Both	Faculty	MLP	Both	*p* value[a]
I use the "palliative care" service for a patient with symptoms and who is . . .							
Newly diagnosed with cancer	7 (16)	11 (26)	18 (21)	20 (45)	21 (40)	41 (43)	.002
Undergoing active primary treatment for cancer (curative intent)	9 (21)	11 (26)	20 (24)	15 (34)	23 (44)	38 (40)	.02
Without evidence of active cancer	7 (16)	11 (26)	18 (21)	10 (23)	10 (19)	20 (21)	.95
Receiving active treatment for advanced cancer (palliative intent)	30 (70)	40 (95)	70 (82)	37 (84)	48 (92)	85 (89)	.24
No longer receiving cancer treatment	35 (81)	31 (74)	66 (78)	32 (73)	39 (75)	71 (74)	.56
I use the "supportive care" service for a patient with symptoms and who is . . .							
Newly diagnosed with cancer	25 (58)	31 (74)	56 (66)	33 (75)	46 (87)	79 (81)	.02
Undergoing active primary treatment for cancer (curative intent)	29 (67)	36 (86)	65 (76)	29 (66)	45 (85)	74 (76)	.98
Without evidence of active cancer	21 (49)	26 (63)	47 (56)	24 (55)	35 (66)	59 (61)	.51
Receiving active treatment for advanced cancer (palliative intent)	33 (77)	37 (88)	70 (82)	38 (86)	52 (98)	90 (93)	.03
No longer receiving cancer treatment	37 (86)	37 (90)	74 (88)	33 (75)	47 (89)	80 (82)	.29

Data are presented as number (%) of respondents who agreed or strongly agreed.
[a]Chi-square or Fisher's exact test used, as appropriate.
Abbreviation: MLP, midlevel providers (including physician assistants and advanced nurse practitioners).

Hui et. al. The Oncologist 2015;20:1326-1332

What's in Name?

- Supportive care vs. Palliative care

Table 3. Differences between "palliative care" and "supportive care" perceived by oncology specialists

Statement	Palliative care, *n* (%)			Supportive care, *n* (%)			
	Hematologic	Solid tumor	Both	Hematologic	Solid tumor	Both	*p* value[a]
I use this service for a patient with symptoms and who is . . .							
Newly diagnosed with cancer	18 (21)	41 (43)	59 (32)	56 (66)	79 (81)	135 (74)	< .001
Undergoing active primary treatment for cancer (curative intent)	20 (24)	38 (40)	58 (32)	65 (76)	74 (76)	139 (76)	< .001
Without evidence of active cancer	18 (21)	20 (21)	38 (21)	47 (56)	59 (61)	106 (58)	< .001
Receiving active treatment for advanced cancer (palliative intent)	70 (82)	85 (89)	155 (85)	70 (82)	90 (93)	160 (88)	.52
No longer receiving cancer treatment	66 (78)	71 (74)	137 (75)	74 (88)	80 (82)	154 (85)	.003
Regarding the service name							
Service name is a barrier for me to refer patients	36 (42)	30 (31)	66 (36)	3 (4)	3 (3)	6 (3)	< .001
Service name is synonymous with hospice and end-of-life care	48 (56)	49 (51)	97 (53)	5 (6)	6 (6)	11 (6)	< .001
Service name can decrease hope in patients and families	53 (62)	53 (55)	106 (58)	7 (8)	7 (7)	14 (8)	< .001
Service name is associated with treatment of chemotherapy side effects	14 (16)	21 (22)	35 (19)	52 (61)	64 (66)	116 (64)	< .001

Data are presented as number (%) of respondents who agreed or strongly agreed.
[a]McNemar test.

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Hui et. al. The Oncologist 2015;20:1326-1332

What's in Name?

- **Reasons for delayed referrals**

  -Patient perceived lack of palliative care needs

  -Possibility of cure in setting of advanced disease

  -Heightened expectations

  -Stigma associated with palliative care

  -Lack of trials in hematological patients

  -Uncertainty of disease trajectory

  -Confidence in provision of supportive care

- Service name changed to Supportive Care
- 41% greater number of palliative care consultations

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Hui et. al. The Oncologist 2015;20:1326-1332

Definition of Supportive Care

(NCI) National Cancer Institute Definition

- Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, palliative care, and symptom management.

Definition of Supportive Care

(WHO) World Health Organization

-Palliative care is an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

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Definition of Supportive Care

(MASCC) Multinational Association of Supportive Care in Cancer

- Supportive care in cancer is the prevention and management of the symptoms and side effects of cancer and its treatment across the cancer continuum from diagnosis to the end of life. It includes support for patients, their families, and their caregivers. At MASCC, we believe that supportive care improves both quality of care and quality of life.

Definition of Supportive Care

(ESMO) European Society for Medical Oncology

- Advocates for patient-centered care (including supportive and palliative care) to be integrated by a multidisciplinary team (MDT) to anticancer treatment, from the time of diagnosis and throughout the continuum of disease, including end-of-life and survivorship care.

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Annals of Oncology, Volume 29, Issue 1, 1 January 2018, Pages 36–43, https://doi.org/10.1093/annonc/mdx757

Areas Encompassing Supportive Care

NCCN GUIDELINES FOR SUPPORTIVE CARE

- Adult Cancer Pain ▸
- Antiemesis ▸
- Cancer- and Chemotherapy-Induced Anemia ▸
- Cancer-Associated Venous Thromboembolic Disease ▸
- Cancer-Related Fatigue ▸
- Distress Management ▸
- Myeloid Growth Factors ▸
- Palliative Care ▸
- Prevention and Treatment of Cancer-Related Infections ▸
- Smoking Cessation ▸
- Survivorship ▸

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ASCO 2017 Updates

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ASCO 2017

- Focus on Palliative Care/Supportive Care timing and benefits of early referrals.

Provision of palliative care services to patients with advanced cancer remains suboptimal

The Daily Briefing-Advisory Board review.

JOURNAL OF CLINICAL ONCOLOGY
Official Journal of the American Society of Clinical Oncology

Integration of Palliative Care Into Standard Oncology Care:

Clinical Practice Guideline Update

“Inpatients and outpatients with advanced cancer should receive dedicated palliative care services early in the disease course, concurrent with active treatment.”

Lung Cancer and Early Palliative Care

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

- Study with NSCLC showed survival that was prolonged by 2 months and clinically meaningful improvements in quality of life and mood
- Resulted in greater documentation of resuscitation preferences in the outpatient EMR as well as less aggressive care at end of life.

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The Daily Briefing-Advisory Board review.
Temel et al. N Engl J Med 2010:733-42

GI and Lung Cancer and Early Palliative Care

VOLUME 35 · NUMBER 8 · MARCH 10, 2017

JOURNAL OF CLINICAL ONCOLOGY | ORIGINAL REPORT

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

Jennifer S. Temel, Joseph A. Greer, Areej El-Jawahri, William F. Pirl, Elyse R. Park, Vicki A. Jackson, Anthony L. Back, Mihir Kamdar, Juliet Jacobsen, Eva H. Chittenden, Simone P. Rinaldi, Emily R. Gallagher, Justin R. Eusebio, Zhigang Li, Alona Muzikansky, and David P. Ryan

- 350 patients enrolled
- Early integration of palliative and oncology care in patients with newly diagnosed incurable cancers improves QOL, reduces depression symptoms, and enhances coping with prognosis and communication about EOL-care preferences.

ASCO 2017

- **Abstract#10121**

Advanced cancer patients' self-reported perception of timeliness of their referral to outpatient supportive/palliative care and their survival data.

- Prospective survey 200 advanced cancer patients.
- Median time of referral 8.5 months before death
- 72% referral was "just in time"
- 21% referral was "late/much too late"
- 7% referral was too early/early

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Wong et al. J Clin Oncol 35, 2017

ASCO 2017

- When should the referral take place?
  - -39% time of diagnosis of cancer
  - -17 % start of first line chemotherapy
  - -24% at diagnosis of recurrent disease
  - -7% no further treatment options
  - -2% never

- No difference in survival among patients who reported their referral was early, just in time, or late.
- Small number of patients

Wong et al. J Clin Oncol 35, 2017

Inpatient Palliative Care during Hematopoietic Stem Cell Transplantation (HCT) Hospitalization Improves Psychological Distress at Six Months Post-HCT

Areej El-Jawahri, Lara Traeger, Harry VanDusen, Joseph Greer, Vicki Jackson, William Pirl, Jason Telles, Sarah Fishman, Alison Rhodes, Thomas Spitzer, Steven McAfee, Yi-Bin Chen, Jennifer Temel

MASSACHUSETTS GENERAL HOSPITAL CANCER CENTER

CORe CANCER OUTCOMES RESEARCH

Background

- HCT is an intensive potentially curative therapy for patients with hematologic malignancies.
- Significant symptom burden → deterioration in patients' QOL & mood during a 3-4 week hospitalization.
- Experience during HCT hospitalization is predictive of post-HCT QOL and psychological outcomes.
- Depression and PTSD symptoms are prevalent in HCT survivors.

Objectives

- Assess the effect of inpatient palliative care integrated with transplant care on patient-reported psychological distress & QOL at six months post-HCT.
- Explore whether improvement in symptom burden & mood during hospitalization for HCT mediates the effect of the palliative care intervention on patient-reported outcomes at six months post-HCT.

Study Design

160 patients with hematologic malignancies within 72 hour of admission for HCT (and their willing caregivers)

RANDOMIZED

Inpatient Integrated Palliative and Transplant Care
- At least 2 visits weekly during HCT hospitalization.

Transplant Care Alone
- Palliative care consult upon request.

Primary outcome (Week 2)

6-month outcomes

Eligibility Criteria

Inclusion criteria:

- Adult patients (≥ 18 years) with hematologic malignancy admitted for HCT
- Ability to speak English or able to complete questionnaires with minimal assistance

Exclusion criteria:

- HCT for benign condition
- Prior history of HCT
- Uncontrolled psychiatric or comorbid condition prohibits compliance with study procedures

Study Measures

- Secondary endpoints at six months post-HCT:
  - QOL (FACT-BMT)
  - Fatigue (FACT-Fatigue)
  - Depression & Anxiety Symptoms (HADS)
  - Depressive Syndrome (PHQ-9)
  - PTSD Symptoms (PCL-Civilian Version)
- Mediators of intervention effect:
  - Symptom Burden (ESAS) at week-2
  - Mood (HADS & PHQ-9) at week-2

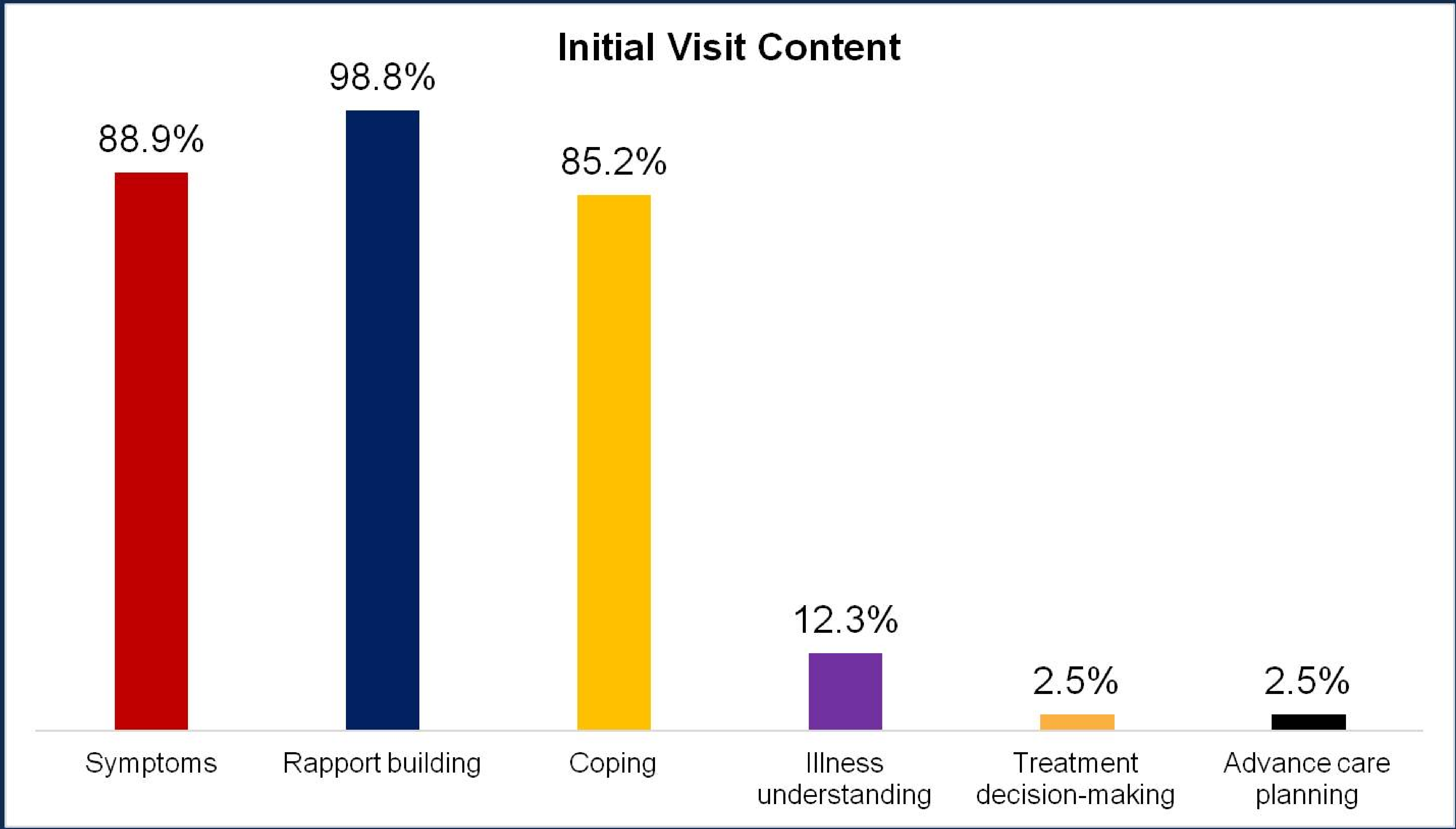
Baseline Demographics

Variable	Control (N=79)	Intervention (N = 81)
Age mean (SD)	56.9 (14.1)	57.2 (12.7)
Female (%)	43 (54.4%)	48 (59.3%)
White Race (%)	70 (88.6%)	69 (85.2%)
Education (%)		
High School	24 (30.4%)	23 (28.4%)
College	42 (53.2%)	35 (43.2%)
Post-Graduate	13 (16.5%)	23 (28.4%)
Married/Partner	55 (69.6%)	63 (77.8%)
Income (%)		
< $50,000	29 (40.3%)	20 (27.4%)
$51,000 – $100,000	19 (26.4%)	29 (39.7%)
>$100,000	24 (33.3%)	24 (32.9%)

Baseline Demographics

Variable	Control (N=79)	Intervention (N = 81)
Diagnosis (%)		
ALL	7 (9.0%)	4 (5.0%)
AML/MDS	23 (29.5%)	24 (30.0%)
MF/CML	7 (9.0%)	8 (10.0%)
Lymphoma	26 (33.3%)	18 (22.5%)
Multiple Myeloma	15 (19.2%)	26 (32.5%)
HCT-Comorbidity Index (SD)	3.3 (2.1)	3.0 (3.3)
ECOG PS (%)		
0	28 (35.4%)	27 (33.3%)
1	49 (62.0%)	54 (66.7%)
2	2 (2.5%)	0 (0.0%)
Transplant type (%)		
Autologous	39 (49.4%)	41 (50.6%)
Myeloablative Allogeneic	14 (17.7%)	16 (19.8%)
RIC Allogeneic	26 (32.9%)	24 (29.6%)

Palliative Care Intervention



Palliative Care Intervention

Initial Visit Symptoms Addressed

65.4%

67.9%

Reporting Interface

Patient Self-R

- Example: Pain

None	I have not had
Grade 1 (Mild)	I have had mil
Grade 2 (Moderate)	I have had mo interferes with normal daily a
Grade 3 (Severe)	I have had sev severely interf
Grade 4 (Disabling)	My pain has b

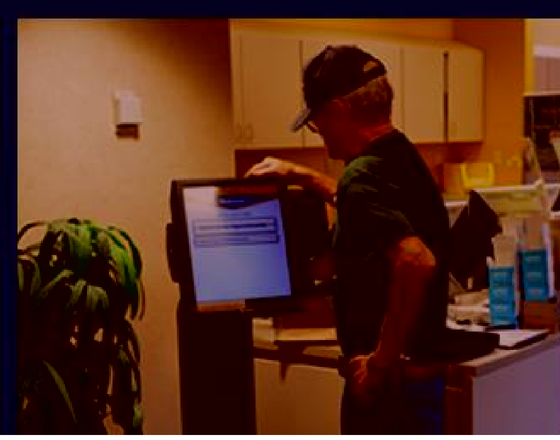
pain.

d pain, but it does not interfere with my normal functioning.

derate pain, and my pain or my use of pain medications my normal functioning. But I am still able to carry out my ctivities.

ere pain, and my pain or my use of pain medications eres with my normal daily activities.

een disabling.



Patient Self-Reporting Interface

- Example: Shortness of Breath (Dyspnea)

None	I have not had shortness of breath (with exercise or rest).
Grade 1 (Mild)	I have been short of breath with exercise, but I can walk up 1 flight of stairs without stopping.
Grade 2 (Moderate)	I have been short of breath with exercise but I am not able to walk up 1 flight of stairs or 1 city block without stopping.
Grade 3 (Severe)	I have been short of breath during my normal daily activities (dressing, showering, cleaning, cooking, etc).
Grade 4 (Disabling)	I have been short of breath even when I am resting in bed or in a chair.

Presented By Ethan Basch at 2017 ASCO Annual Meeting

Email Alert to Clinical Nurse

From: Patient Symptom Tracking <webmaster@mskcc.org>
Date: Wednesday, June 14, 2010 at 2:16 PM
To: Microsoft Office User < [redacted]@mskcc.org>
Subject: Patient Symptom Alert

SYMPTOM REPORTED FROM HOME

Patient Medical Record Number: [redacted]
Date/Time Reported: 07/14/2010 at 2:15 PM

Symptom: DYSPNEA **Grade:** 3

Symptoms that have worsened since 07/07/2010:
Symptom: DYSPNEA from **Grade:** 1 to 3

Link to FULL REPORT

Printed Report to Oncologist at Clinic Visit

STAR SYMPTOM REPORT
Confidential PHI

Patient Name: [redacted]
Patient MRN: [redacted]
Primary Oncologist: [redacted]

Worsened symptoms since July 7:

- Cough: from grade 0 to grade 1

Improved symptoms since July 7:

- Dyspnea: from grade 3 to grade 1
- Fatigue: from grade 2 to grade 1
- Pain: from grade 1 to grade 0

Below is a summary of prior reported symptoms, with most recent reports on top:

DATE	Anorex.	Constip.	Cough	Diarrhea	Dyspnea	Dysur.	Fatigue	Hot Fl.	Nausea	Neurop.	Pain	Vomiting
06/10/10	0	0	1	0	2	0	2	0	2	0	1	0
06/10/10	Clinic/Chemotherapy Visit											
06/20/10	0	0	2	0	1	0	2	0	0	0	1	0
07/01/10	0	0	1	0	1	0	1	0	0	0	1	0
07/01/10	Clinic/Chemotherapy Visit											
07/07/10	0	0	0	0	1	0	1	0	1	0	0	0
07/14/10	0	0	0	0	3	0	2	0	0	0	1	0
07/22/10	0	0	1	0	1	0	1	0	0	0	0	0
07/22/10	Clinic/Chemotherapy Visit											

Results

- 766 patients enrolled between June 2007 and January 2011
- Overall survival analysis June 2016
  - Median follow-up 7 years
  - 517/766 (67%) participants had died

BASELINE CHARACTERISTICS		Standard Care Arm (N=325)*	Self-Reporting Arm (N=441)*
Age - median (range)		**62** (26-88)	**61** (30-91)
Female sex – no. (%)		187 (**58%**)	257 (**58%**)
Race – no. (%)	White	283 (**87%**)	377 (**86%**)
	Black	24 (**7%**)	43 (**10%**)
	Asian	18 (**6%**)	21 (**5%**)
Cancer type – no. (%)	Genitourinary	102 (**31%**)	143 (**32%**)
	Gynecologic	80 (**25%**)	97 (**22%**)
	Breast	54 (**17%**)	89 (**20%**)
	Lung	89 (**27%**)	112 (**25%**)
Education – no. (%)	≤High School	64 (**20%**)	106 (**24%**)
	College	155 (**48%**)	205 (**47%**)
	Graduate Degree	106 (**33%**)	130 (**30%**)
Quality of Life – mean (range)		**84** (20–100)	**85** (27–100)

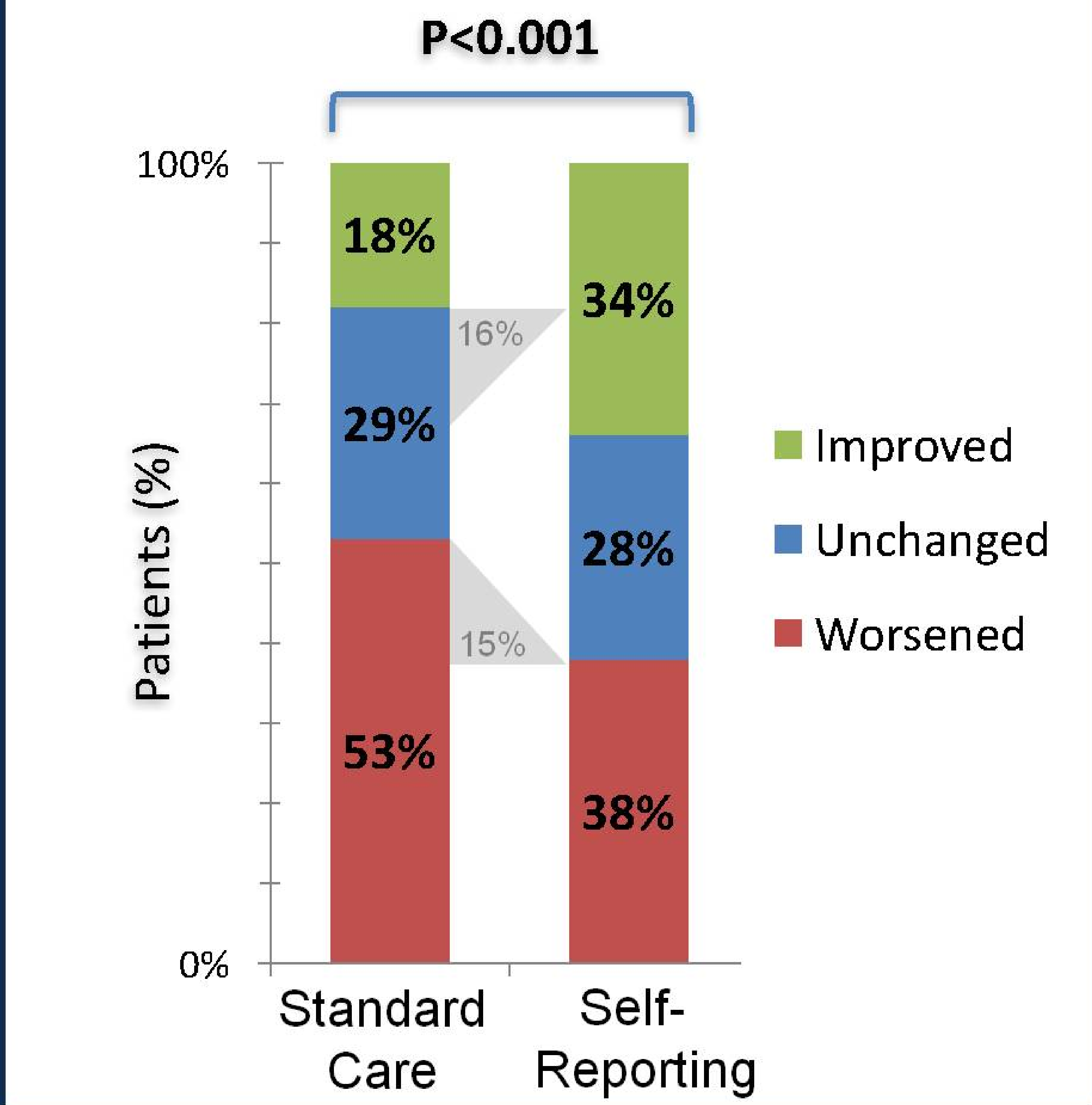
* 2:1 stratified randomization favoring self-reporting arm for 227 participants lacking baseline computer experience (J Clin Oncol 2016;34:557-565)

Patient Participation

- Patients self-reported symptoms 73% of the time when prompted to do so
- Nurses took action in response to alerts 77% of the time
  - Counselling, supportive medications, referrals to ER, chemotherapy dose modifications, imaging

Quality of Life

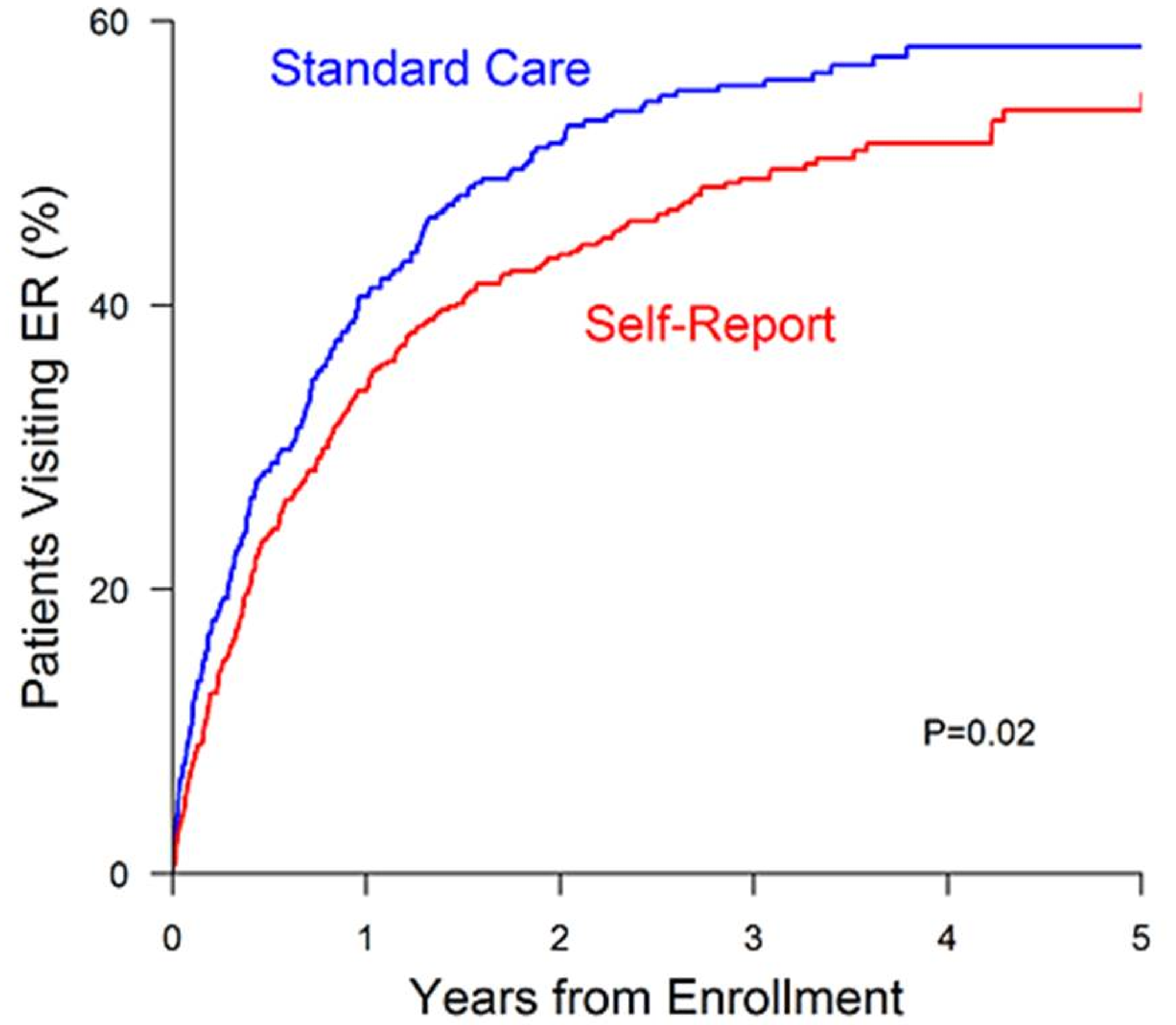
- Assessed at 6 months, compared to baseline
- Compared to standard care, 31% more patients in the self-reporting arm experienced QOL benefits (*P<0.001*)



Basch: J Clin Oncol 2016;34:557-565

Proportion of Patients Visiting Emergency Room

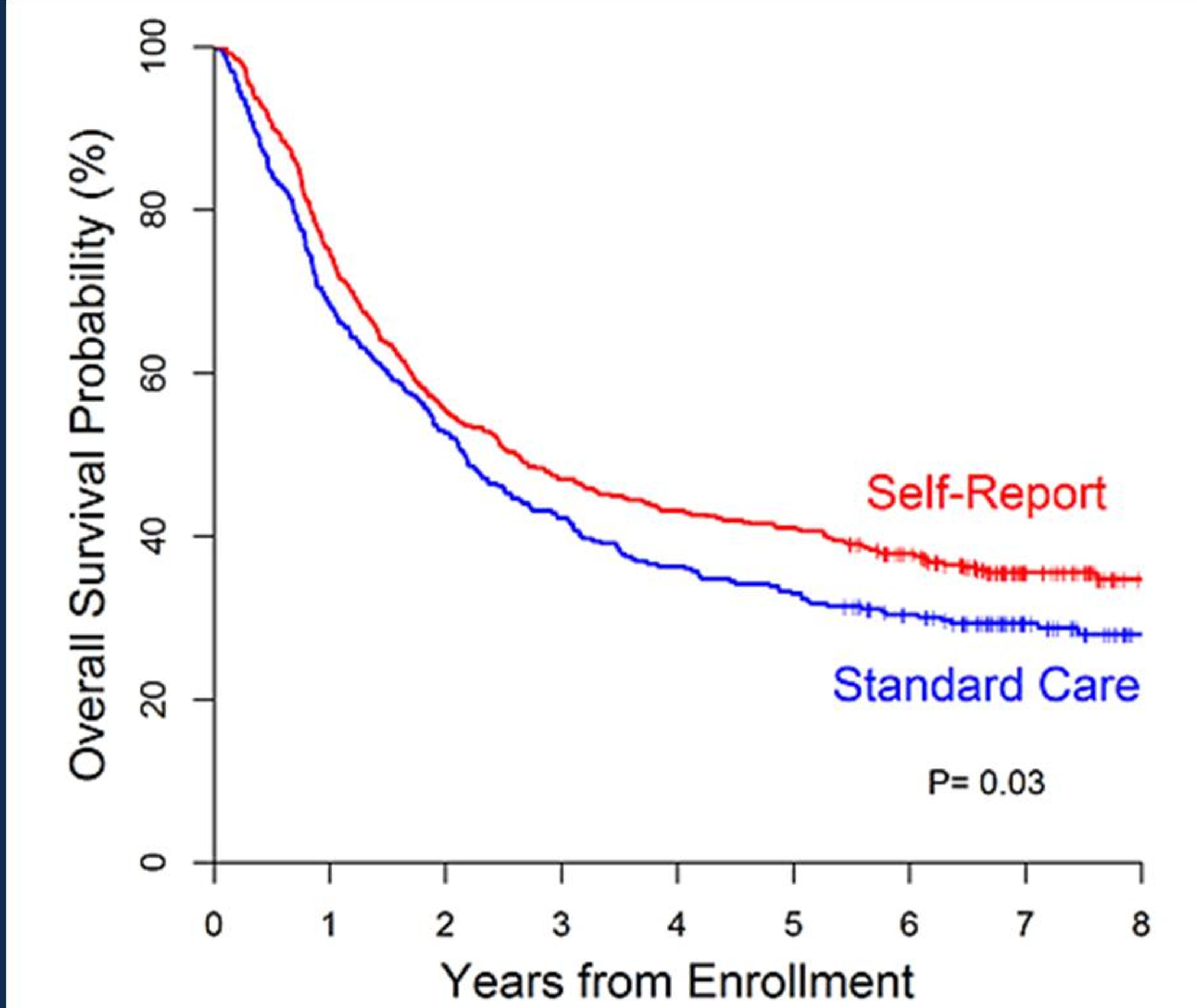
- Compared to standard care, 7% fewer patients in the self-reporting arm visited the ER, with durable effects throughout the study (*P=0.02*)



	0	1	2	3	4	5
Total	766	554	415	344	308	288
Self-Report	441	331	244	207	190	181
Standard	325	223	171	137	118	107

Overall Survival

- Compared to standard care, median survival was 5 months longer among patients in the self-reporting arm (31.2 vs. 26.0 months) (*P=0.03*)
- Remained significant in multivariable analysis: Adjusted hazard ratio 0.832 (*95% CI; 0.696, 0.995*)

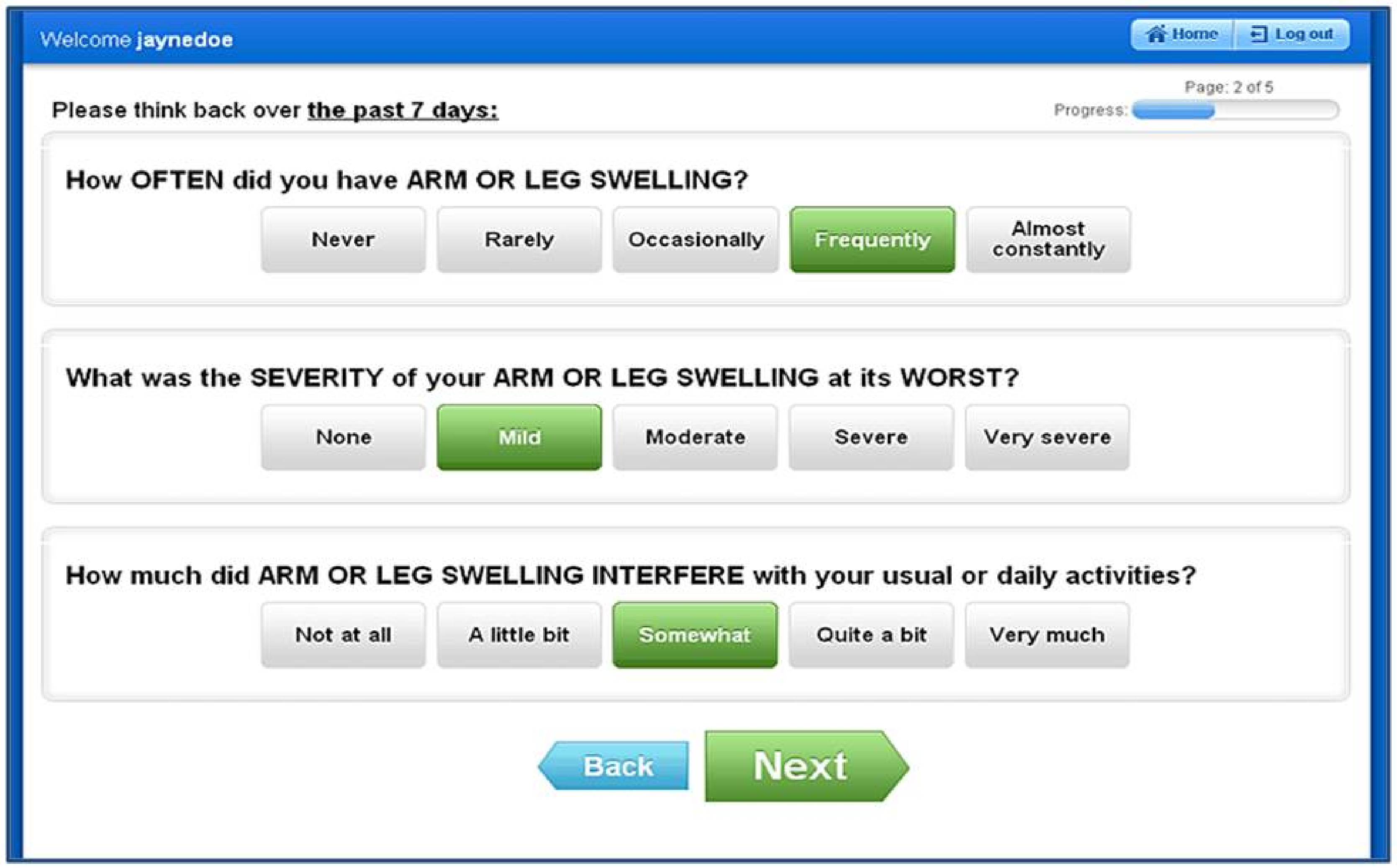


Total	766	554	415	344	308	288	237	115	60
Self-Report	441	331	244	207	190	181	148	65	33
Standard	325	223	171	137	118	107	89	50	27

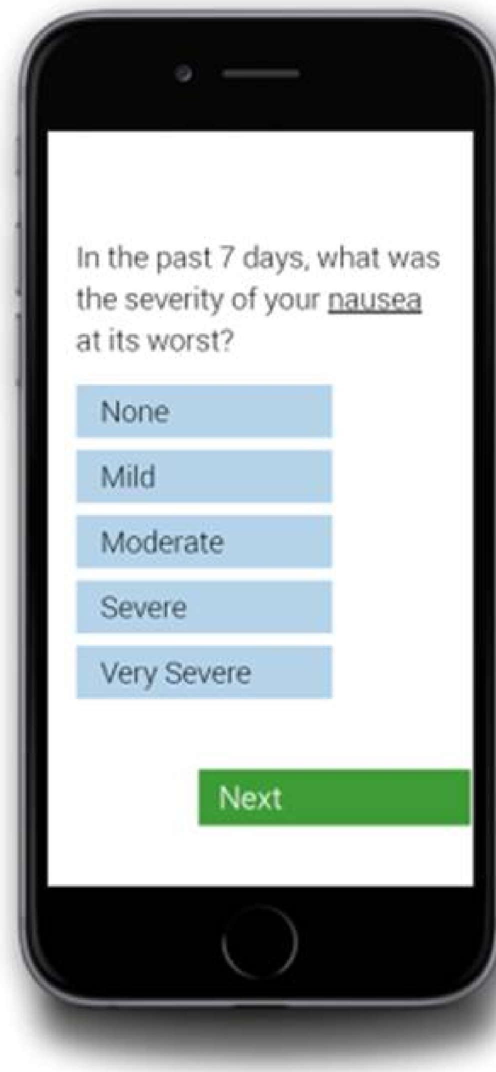
Conclusions

- Systematic symptom monitoring with patient self-reporting improves overall survival
- This approach should be considered for inclusion as a part of standard symptom management
- Future efforts should focus on implementation strategies for integrating self-reporting into electronic health records and into workflow of oncology practice

Next Generation of Systems



Web



Mobile

Automated Telephone Systems

Updates in CINV

- Phase III study if NEPA, a fixed combination of netupitant and palonestron, versus an aprepitant regimen for prevention of chemotherapy induced nausea and vomiting (CINV)
- Abstract #10090

-Results showed to be non-inferior.
-First study comparing NKI/RA regimens.

Updates in CINV

FDA Warns on Anaphylaxis With IV Rolapitant for CINV

Zosia Chustecka

DISCLOSURES | January 16, 2018

A warning about anaphylaxis, anaphylactic shock, and other hypersensitivity reactions occurring with the use of intravenous (IV) rolapitant (*Varubi*, Tesaro Inc) in patients with cancer has been highlighted by the US Food and Drug Administration in a MedWatch bulletin.

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Updates in CINV

- **New agents**

-Syndros (dronabinol)

-Liquid formulation 4.2 mg/m2 (max 12.6mg/m2)

-Contains 50% dehydrated alcohol

-Anorexia associated with weight loss in patients with AIDS

-CINV who have failed to respond adequately to conventional antiemetics

-Administered 1-3 hrs prior to chemotherapy then every 2-4 hrs after chemo

-First dose taken on an empty stomach at least 30 minutes prior to eating

- Drink full glass of water right after taking a dose

Extended-release granisetron subq injection (Sustol®)

-FDA approval: prevention of aCINV and dCINV with MEC or AC regimens

-Dosage 10 mg 30 minutes prior chemotherapy.

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Co

CONCLUSIONS

- Discussion on palliative care referrals should occur early on?
  -Earlier studies showed improvement in QoL
  -Recent studies showing impact in coping strategies with early integrated palliative care.
  -Palliative care improved depression and PTSD in SCT patients
  - Economic impact (decrease cost) with use of palliative care services
  -Increase and support education and training to Physicians, APPs/nurses/staff

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CONCLUSIONS

Differences in terms needs to be explained to the patient.

-More advocacy for patients/discussion palliative care

-Research needed on a more diverse ethnic population and in hematologic malignancies.

- Supportive care name change?

-Divide palliative and supportive care?

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CONCLUSIONS

-NEPA non-inferior to aprepitant NKI/RA regimen
-Many options for nausea (dronabinol)
-Medicinal marijuana?
-Consider more innovative approaches like integration of care with patients and EMR reporting to support patients during treatment.

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TEAM WORK

Resources

(ESMO) European Society for Medical Oncology

ESMO resources for integrated patient-centred care education

ESMO already offers a wide array of educational programmes and tools to oncologists in the domain of patient-centred care (see Table 3).

Table 3.

ESMO resources for integrated patient-centred care education

• **E-learning modules**[a] on supportive and palliative care
• **ESMO Palliative Care Fellowships**[b] ESMO provides two palliative care fellowships allowing recipients observation or research at one of the ESMO Designated Centres
• **ESMO Clinical Practice Guidelines**[c] including guidelines on supportive care and palliative care.
• **ESMO Patient Guides**[d] include, e.g. how to deal with side-effects

Annals of Oncology, Volume 29, Issue 1, 1 January 2018, Pages 36–43, https://doi.org/10.1093/annonc/mdx757

Accreditation

(ESMO) European Society for Medical Oncology

- Designated centers of Integrated Oncology and Palliative Care. Accreditation based on recommendations of World Health Organization (WHO) on provision of palliative care for patients with cancer.

<u>Objectives:</u>

-Integration of palliative care into existing guidelines.

-Encouraging palliative care education and training for medical oncologists as well as other healthcare professionals

-Expanding cooperation with other organizations in supporting and sustaining palliative care development

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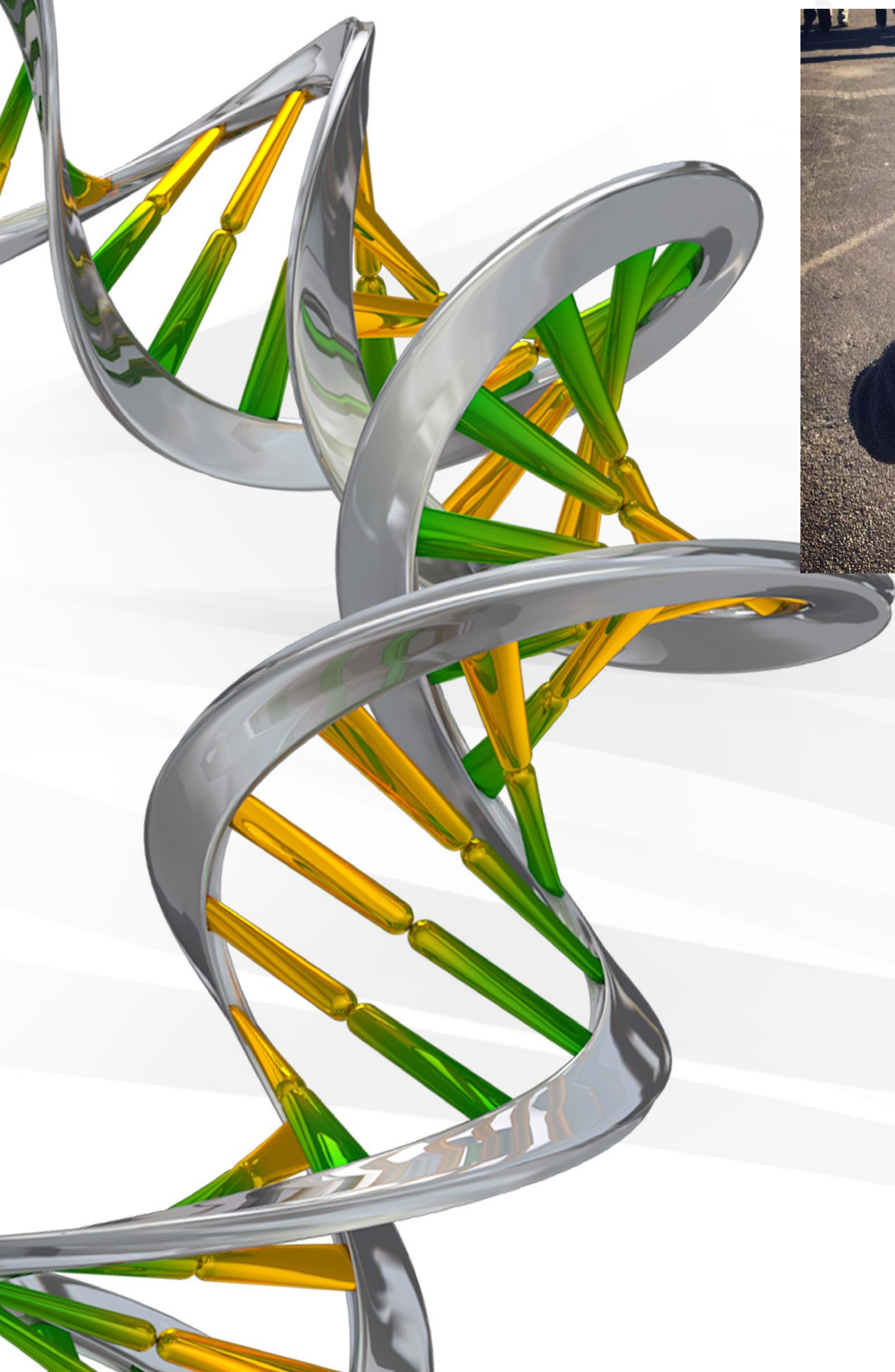
How do you define Supportive Care?



Thank You!

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