

CAGPO 2015: Advance Care Planning and Discussing End of Life Care



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Financial Interest Disclosure

(over the past 24 months)

Dr. Michael Hartwick

I receive a salary as Regional Medical Lead for Trillium Gift of Life (Ontario's organ and tissue donation organization) since 2014.

CAGPO 2015: Advance Care Planning and Discussing End of Life Care

1. Recognize the need to consider and discuss EOL issues early in cancer care.
2. Discuss individual and institutional strategies to support early communication about EOL care plans with cancer patients



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A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients

The Study to Understand Prognoses and Preferences
for Outcomes and Risks of Treatments (SUPPORT)

The SUPPORT Principal Investigators

- 9100 Patients
- 5 American hospitals
- 6 month mortality of 47%

SUPPORT, JAMA, 1995



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A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients

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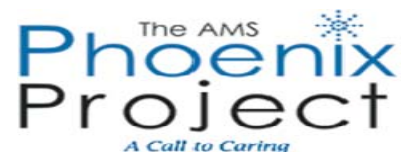
The SUPPORT Principal Investigators

- 47% of physicians knew their patients preference for CPR
- 46% of DNR orders were written within 2 days of death
- 38% of patients who died spent at least 10 days in ICU and reports of moderate to severe pain were common

SUPPORT, JAMA, 1995



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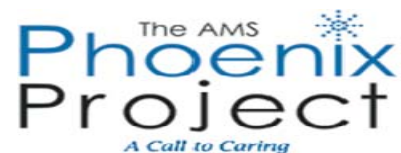
The SUPPORT Principal Investigators

“... Greater individual and societal commitment and more
provocative measures may be needed”.

SUPPORT, JAMA, 1995



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What matters most in end-of-life care: perceptions of seriously ill patients and their family members

Daren K. Heyland, Peter Dodek, Graeme Rucker, Dianne Groll, Amiram Gafni, Deb Pichora, Sam Shortt, Joan Tranmer, Neil Lazar, Jim Kutsogiannis, Miu Lam, for the Canadian Researchers, End-of-Life Network (CARENET)

- 434 Patients (37.7 % Cancer)
- 5 Canadian hospitals
- Rank 28 element in terms of importance to EOL care

Heyland, CMAJ., 2006



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1. To have trust and confidence in the doctors looking after you (55.8%)
2. Not to be kept alive when there is little hope for a meaningful recovery (55.7%)
3. That information about your disease be communicated to you by your doctor in a honest manner (44.1%)

Heyland, CMAJ., 2006



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Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning

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for the ACCEPT (Advance Care Planning Evaluation in Elderly Patients) Study Team and the Canadian Researchers at the End of Life Network (CARENET)

- 278 Patients (19.4 % Cancer)
- 12 Canadian Hospitals
- 3% In-Hospital Mortality

Heyland, JAMA Intern Med., 2013



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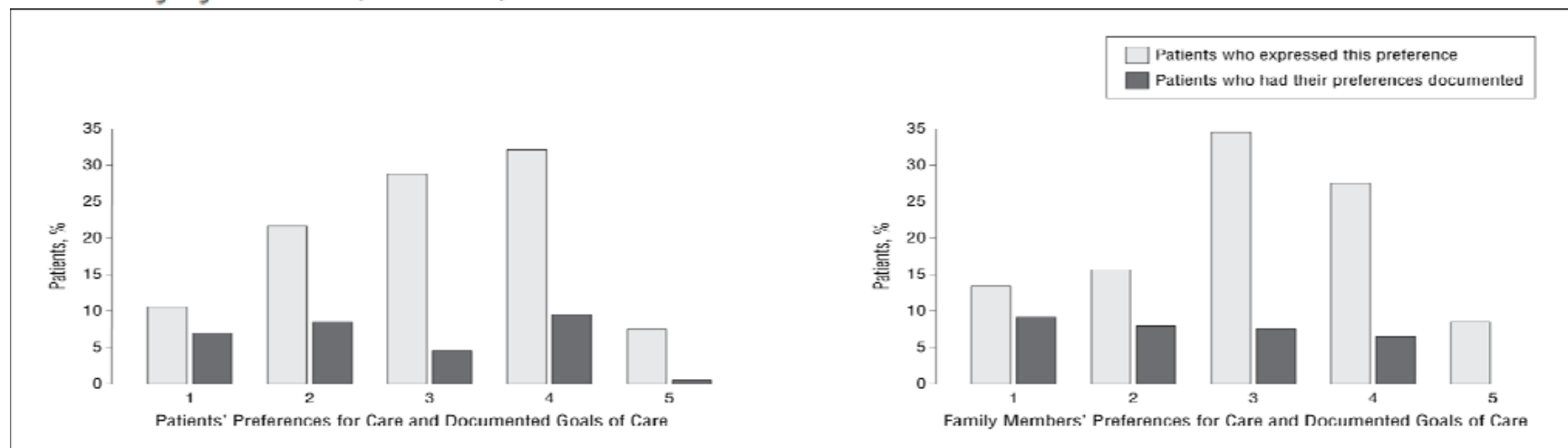
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Heyland, JAMA Intern Med., 2013

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- 76.3% had considered what kinds of LST they would want
- 30.3% had discussed these preferences with FMD
- 17.0% had discussed these preferences with Specialist
- 30.2% Agreement between patients' preferences for EOL care and documentation in the medical record.

Heyland, JAMA Intern Med., 2013



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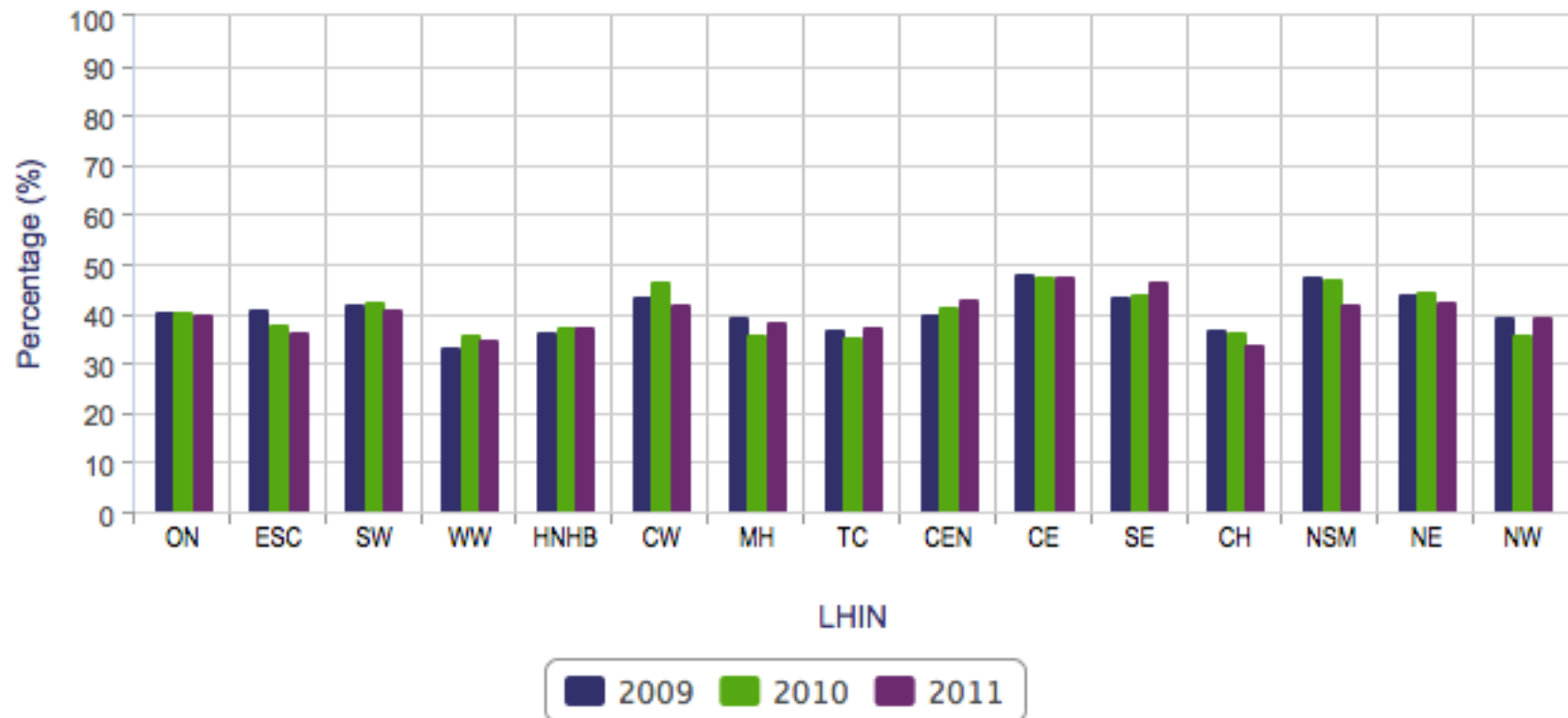


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End-of-Life Care

Figure 1: Percentage of cancer patients who visited the emergency department (ED) in the last two weeks of life, 2009–2011, by Local Health Integration Network (LHIN)



Report Date: February 2015

Source: OCR, NACRS, DAD

Prepared by: Analytics and Informatics, Cancer Care Ontario



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Emergency Room Use By Patients' with Cancer at the End of Life



Advance Care Planning In Cancer Patients Attending the Emergency Department. (N= 227)		
Indicator	Yes	No OR Unknown
'Do Not Resuscitate' (DNR) order documented	19.8% (n 45)	80.2% (n 182)
Power of Attorney (POA) Known/Appointed	13.7% (31)	86.3% (n 196)
Advance Care Directives	11% (n 25)	89% (n 202)
Currently Receiving Home Care Services	43.2% (n 98)	56.8% (n 129)
Referred to Palliative Care Program	12.3% (n 28)	87.7% (n 199)

Time from admission to death: 6.6 days (± 4.6) 0 -18 days

Time for DNR to be established: 3 days (± 3.5) 0 -14 days.

Time for Goals of Care to be clarified: 3.5 days (± 3) 0-14 days

Fitzgibbon, Sup Canc Care, 2010



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When to Approach the Patient



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Just ask: discussing goals of care with patients in hospital with serious illness

John J. You MD MSc, Robert A. Fowler MD MS, Daren K. Heyland MD MSc; on behalf of the Canadian Researchers at the End of Life Network (CARENET)

1. 55 years
 - a) Advanced organ failure
 - b) Cancer (metastatic cancer or stage IV lymphoma)
 - c) End-stage dementia
2. 80 years of age admitted due to an acute medical or surgical condition.
3. Would I be surprised if this patient died within the next year?

You, CMAJ., 2014



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ECOG Performance Status Scale	
Grade	Description
0	Normal activity. Fully active, able to carry on all pre-disease performance without restriction.
1	Symptoms but ambulatory. Restricted in physically strenuous activity, but ambulatory and able to carry out work of a light or sedentary nature (<i>e.g.</i> , light housework, office work).
2	In bed <50% of the time. Ambulatory and capable of all self-care, but unable to carry out any work activities. Up and about more than 50% of waking hours.
3	In bed >50% of the time. Capable of only limited self-care, confined to bed or chair more than 50% of waking hours.
4	100% bedridden. Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair.
5	Dead.



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Palliative Performance Scale (PPSv2)
version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with Effort</i> Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-



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Illness and Symptom Trajectory

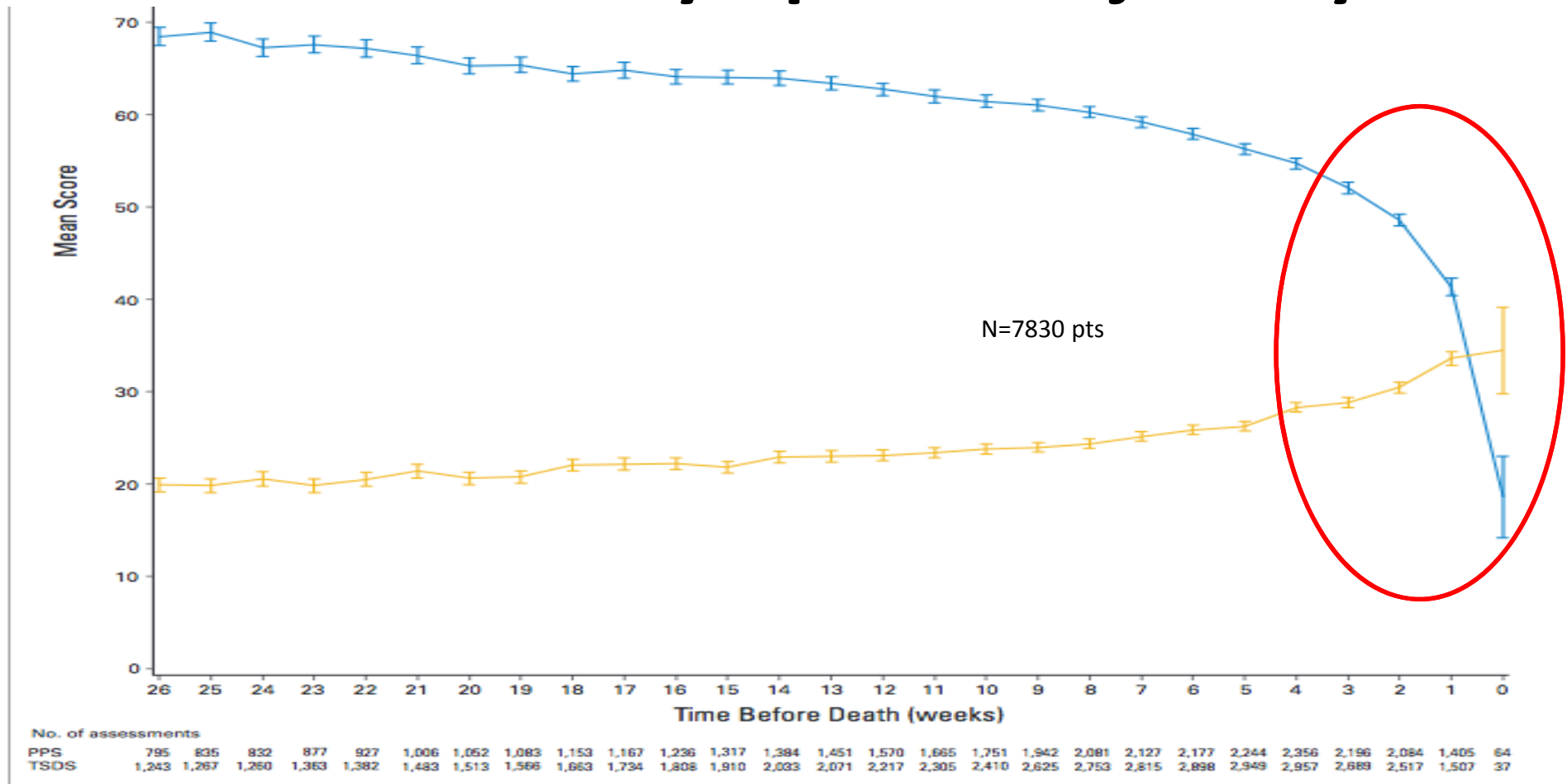


Fig 1. Mean Edmonton Symptom Assessment System (total symptom distress score [TSDS]) and Palliative Performance Scale (PPS) score. (*) Values below data points represent the total number of complete assessments available at a given week. Bars represent 95% CIs for the respective mean scores.

Seow, JCO., 2011

Barriers



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JOURNAL OF ONCOLOGY PRACTICE



The Authoritative Resource for Oncology Practices

Oncologists' Strategies and Barriers to Effective Communication About the End of Life

By Leeat Granek, PhD, Monika K. Krzyzanowska, MD, MPH, Richard Tozer, MD, and Paolo Mazzotta, MD

Ben Gurion University of the Negev, Be'er Sheva, Israel; Princess Margaret Hospital; Sunnybrook Health Sciences Centre; University of Toronto, Toronto; and Juravinski Cancer Centre, Hamilton Ontario, Canada

- 20 Oncologists
- 3 Canadian Centres
- Interviewed about their experiences discussing EOL with patients
- Qualitative – Grounded Theory

Granek, J Oncol Pract. 2013



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Oncologists' Barriers to Communication about End of Life

1. Discomfort with Death and Dying and Palliative Care Stigma
2. The “Death Defying” Mode
3. Patient and Family Reluctance
4. Team Dynamics and Responsibilities
5. Lack of Experience, Good Mentorship, Tools and/or Training

Adapted from; Granek, J Oncol Pract. 2013



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Discomfort with Death and Dying and Palliative Care Stigma



World Health Organization, 1990

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



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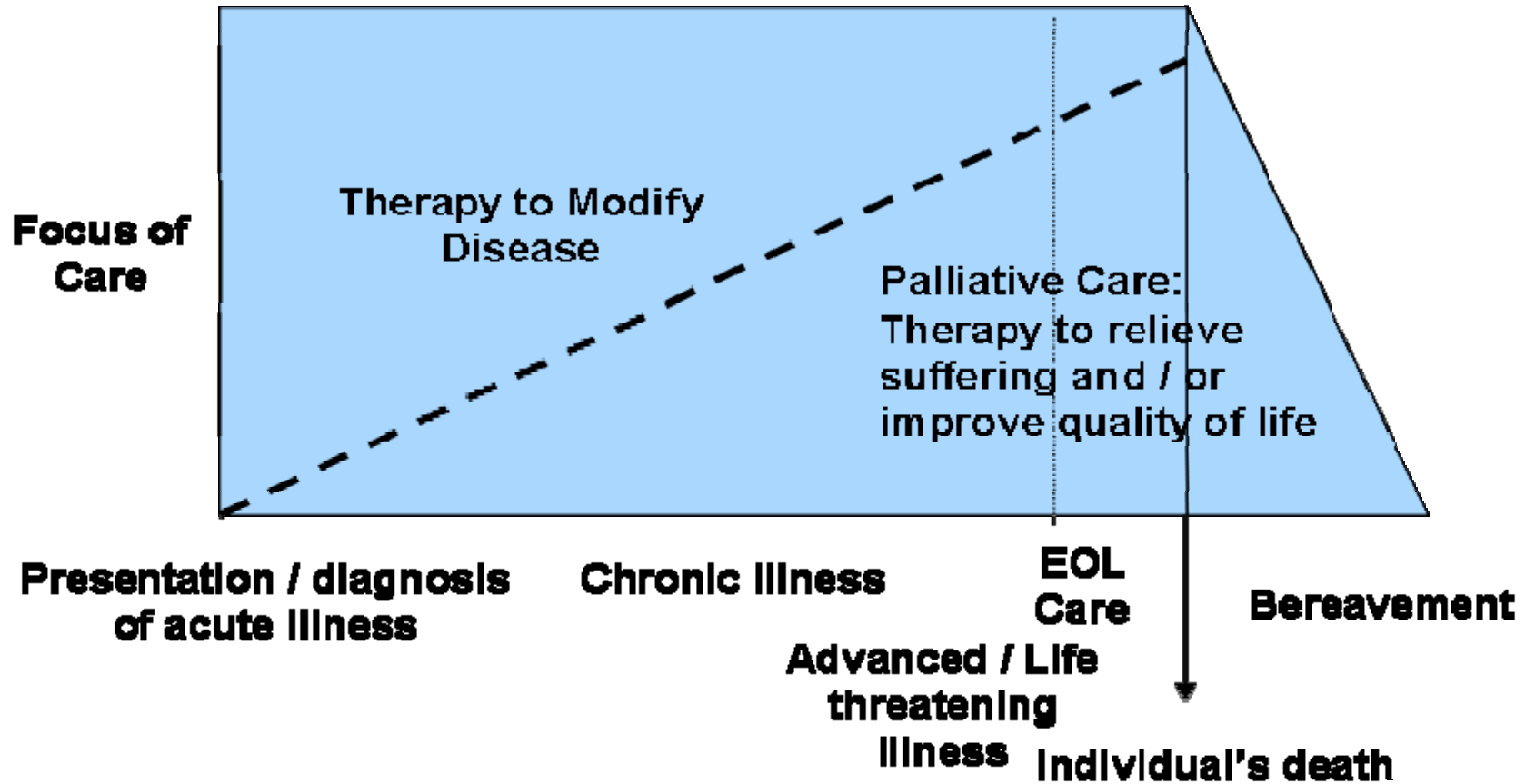
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Discomfort with Death and Dying and Palliative Care Stigma



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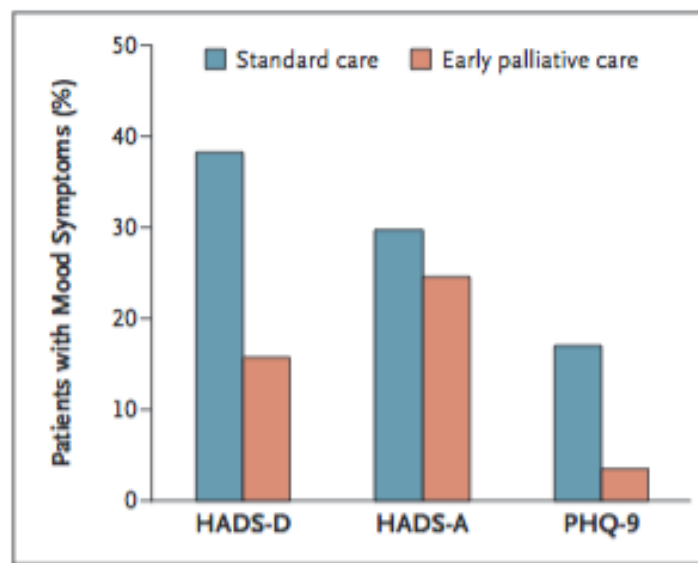
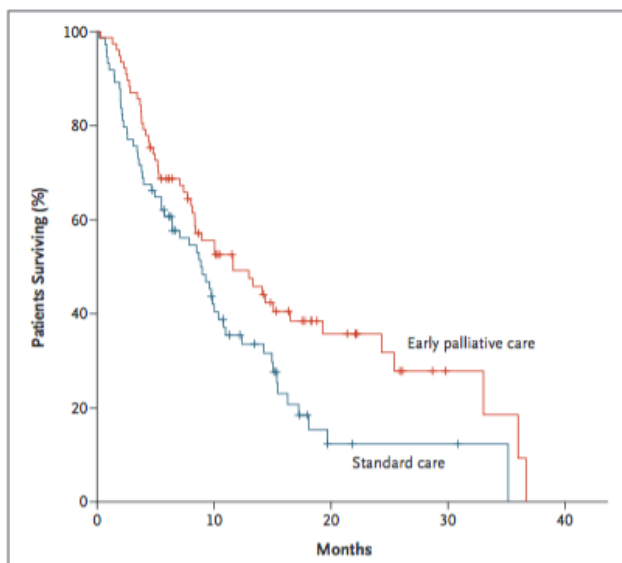
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ORIGINAL ARTICLE

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.



Temel, NEJM. 2010



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The "Death Defying" Mode

NEWS

MAY 8 **Thanks for helping us change cancer forever**
The Society wraps up April Daffodil campaign.

EVENTS

MAY 23 **Cops for Cancer Mississauga Corporate Community Challenge**
Police officers and emergency service personnel organize head shaves, bike rides

Facebook



Canadian Cancer Society

Like

60,366 people like Canadian Cancer Society.



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Patient and Family Reluctance



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What matters most in end-of-life care: perceptions of seriously ill patients and their family members

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3. That information about your disease be communicated to you by your doctor in a honest manner (44.1%)

Heyland, CMAJ., 2006



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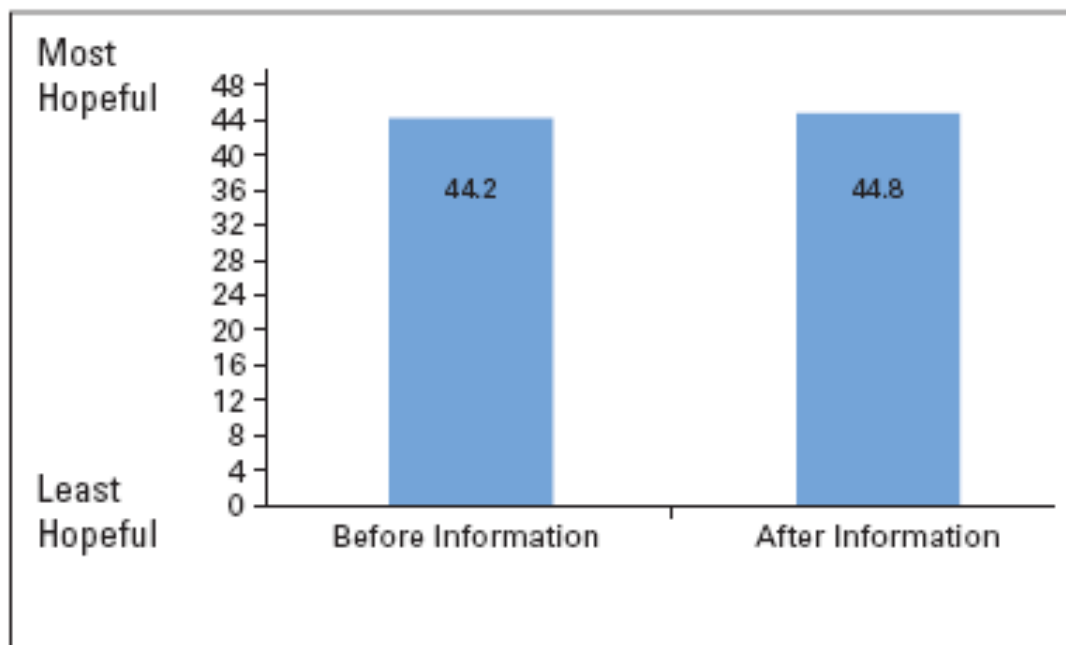


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THOMAS J. SMITH, MD
LINDSAY A. DOW, MD
ENID VIRAGO, M.Div.
JAMES KHATCHERESSIAN, MD
LAUREL J. LYCKHOLM, MD
ROBIN MATSUYAMA, PhD
Massey Cancer Center
Virginia Commonwealth University
Richmond, Virginia

Giving Honest Information to Patients With Advanced Cancer Maintains Hope



- 27 Patients
- Printed Decision Aids
- No Survival and Cure
- Pre/post Herth Hope Index

Fig 1. The effect of truthful information on the Herth Hope Index. Hope does not change with honest cancer information about prognosis and options. Data adapted with permission.²

Smith, Oncology. 2010



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SYNOPSIS

What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families

John J. You MD MSc, Peter Dodek MD MHSc, Francois Lamontagne MD MSc, James Downar MD MSc, Tasnim Sinuff MD PhD, Xuran Jiang BM MSc, Andrew G. Day MSc, Daren K. Heyland MD MSc; for the ACCEPT Study Team and the Canadian Researchers at the End of Life Network (CARENET)



- 5 Elements – Preferences for care, Values, Prognosis, Fears or Concerns, Goals of Care
- Addressing more elements increase concordance with goals of care.
- Greater patient satisfaction

You, CMAJ. 2014



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The NEW ENGLAND
JOURNAL of MEDICINE

A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU

Alexandre Lautrette, M.D., Michael Darmon, M.D., Bruno Megarbane, M.D., Ph.D.,
Luc Marie Joly, M.D., Sylvie Chevret, M.D., Ph.D., Christophe Adrie, M.D., Ph.D.,
Didier Barnoud, M.D., Gérard Bleichner, M.D., Cédric Bruel, M.D.,
Gérald Choukroun, M.D., J. Randall Curtis, M.D., M.P.H., Fabienne Fieux, M.D.,
Richard Galliot, M.D., Maité Garrouste-Orgeas, M.D., Hugues Georges, M.D.,
Dany Goldgran-Toledano, M.D., Mercé Jourdain, M.D., Ph.D., Georges Loubert, M.D.,
Jean Reignier, M.D., Fayçal Saidi, M.D., Bertrand Souweine, M.D., Ph.D.,
François Vincent, M.D., Nancy Kentish Barnes, Ph.D., Frédéric Pochard, M.D., Ph.D.,
Benoit Schlemmer, M.D., and Elie Azoulay, M.D., Ph.D.

VALUE based communication reduced the
incidence of depression and post-traumatic stress
in family member 3 months after WLST



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Effect of Communication Skills Training for Residents and Nurse Practitioners on Quality of Communication With Patients With Serious Illness

A Randomized Trial

J. Randall Curtis, MD, MPH^{1,2}; Anthony L. Back, MD³; Dee W. Ford, MD, MSCR⁴; Lois Downey, MA¹; Sarah E. Shannon, PhD, RN²; Ardith Z. Doorenbos, PhD, RN²; Erin K. Kross, MD¹; Lynn F. Reinke, PhD, RN^{2,5}; Laura C. Feemster, MD, MS^{1,5}; Barbara Edlund, PhD, ARNP⁶; Richard W. Arnold, MD⁷; Kim O'Connor, MD⁷; Ruth A. Engelberg, PhD¹

The intervention was associated with significantly increased depression scores among patients of post-intervention trainees

Curtis, JAMA. 2013

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Ben Gurion University of the Negev, Be'er Sheva, Israel; Princess Margaret Hospital; Sunnybrook Health Sciences Centre; University of Toronto, Toronto; and Juravinski Cancer Centre, Hamilton Ontario, Canada

They ask me to see somebody stat one day and they said the patient is going to die within days and I said, "Is the patient DNR?," and the response was "No, but somebody should have that discussion." And I said "Well the somebody should be you because you're the doctor and you've known them for the last couple of years."

Granek, J Oncol Pract. 2013



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Team Dynamics and Responsibilities



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Exploring the Context for Teaching and Learning Communication Skills in Postgraduate Medical Education: A Qualitative Analysis

Amanda Roze des Ordon, Rola Ajjawi, John Macdonald, Aimee Sarti, Michael Hartwick

*“But it's 2 am, you know, I don't want to... I'm by myself here and if he codes tonight... And I like dissuaded him from something and then I find out in the morning that it was... he's never talked about this with his family... I just felt really stuck like just really alone and isolated in this conversation that you basically have to have because you've got to fill out all the sheets or whatever.
(Trainee)*



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Focus on Treatment Plan not the Form

		PHYSICIAN'S ORDERS ORDONNANCES MÉDICALES	
Medication Allergies/Reactions <input type="checkbox"/> none known-aucune connue		Substances or Food Allergies/Reactions <input type="checkbox"/> none known-aucune connue	
CONSULT, TEST, NON MEDICATION TREATMENT, BLOOD TEST DEMANDE DE CONSULTATION, EXAMEN, TRAITEMENT NON MÉDICAMENTEUX, EXAMEN SANGUIN			
CARDIOPULMONARY RESCUCITATION AND PLAN OF TREATMENT RÉANIMATION CARDIOPULMONAIRE ET PLAN DE TRAITEMENT			
SECTION 1: PLAN OF TREATMENT OPTIONS (Please select one of the following):			
<input type="checkbox"/> CATEGORY 1 full treatment including ICU/CCU and CPR			
<input type="checkbox"/> CATEGORY 2 full treatment including ICU/CCU but no CPR			
<input type="checkbox"/> CATEGORY 3 full treatment excluding ICU/CCU/CPR and allow natural death			
<input type="checkbox"/> if elaboration is needed on the above plan of treatment option, please specify: e.g Cat 2, no intubation			
NB: if this patient's plan of treatment excludes CPR but the patient requires a medical or surgical intervention where CPR could reverse a risk associated with that procedure, physician must complete CPR Orders Prior to Medical or Surgical Procedure.			
MRP-MPR (most responsible physician-médecin le plus responsable) Signature		Printed name-Nom en lettres moulées	
		Date (yyaa/mm/dj)	
		Time-Heure	
SECTION 2: DISCUSSED WITH (check all that apply):			
<input type="checkbox"/> patient			
<input type="checkbox"/> substitute decision maker named			
<input type="checkbox"/> family			
<input type="checkbox"/> consensus reached			
<input type="checkbox"/> MD plan of treatment			
<input type="checkbox"/> family aware			
MRP-MPR (most responsible physician-médecin le plus responsable) Signature		Printed name-Nom en lettres moulées	
		Date (yyaa/mm/dj)	
		Time-Heure	
Updates			
<input type="checkbox"/> I have verified that the above noted plan of treatment and CPR is current and valid for this admission.			
MRP-MPR (most responsible physician-médecin le plus responsable) Signature		Printed name-Nom en lettres moulées	
		Date (yyaa/mm/dj)	
		Time-Heure	
<input type="checkbox"/> I have verified that the above noted plan of treatment and CPR is current and valid for this admission.			

FULL TREATMENT

JOURNAL OF PAIN AND SYMPTOM MANAGEMENT

Improving End-of-Life Communication and Decision Making: The Development of a Conceptual Framework and Quality Indicators

[Tasnim Sinuff](#), MD, PhD, [Peter Dodek](#), MD, MHSc, [John J. You](#), MD, MSc, FRCPC, [Doris Barwich](#), MD, CCFP, [Carolyn Tayler](#), RN, BN, MSA, CON (C), [James Downar](#), MDCM, MHSc, FRCPC, [Michael Hartwick](#), MD, MEd, FRCPC, [Christopher Frank](#), MD, FCFP, [Henry T. Stelfox](#), MD, FRCPC, PhD, [Daren K. Heyland](#), MD, FRCPC, MSc  

We have developed a conceptual framework and refined list of 34 quality indicators that can be used by researchers and healthcare decision-makers to evaluate and improve the quality of end of life communication and decision-making.



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Care Consistent with Patient's Values and Goals



Outcome

Processes

Structure

Advance Care Planning

- Conversations about values, wishes & preferences
- Appointment of a Substitute Decision Maker
- Development of Advance Care Plans and Instructional directive (where applicable)

- Advance care planning documents
- Goals of care documents (MOST, POLST, other goals of care forms)
- Care Plans

Documentation

Decisions about Goals of Care or consent for treatment

- Clarification of previous ACP conversations; values; preferences
- Information re Diagnosis; Prognosis; Risks/benefits of treatment
- Options for care & treatment

Organizational and System Aspects (context specific)

Home or Community Settings

Institutionalized Settings



Exploring the Context for Teaching and Learning Communication Skills in Postgraduate Medical Education: A Qualitative Analysis

Amanda Roze des Ordon, Rola Ajjawi, John Macdonald, Aimee Sarti, Michael Hartwick

*“And the staff actually briefed me on how to approach it. I had a fabulous staff at this time... And we went into the room together and he asked me to take charge of the conversation, so I did.
(Trainee)*



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Oncologists' Barriers to Communication about End of Life

1. Discomfort with Death and Dying and Palliative Care Stigma
2. The “Death Defying” Mode
3. Patient and Family Reluctance
4. Team Dynamics and Responsibilities
5. Lack of Experience, Good Mentorship, Tools and/or Training

Adapted from; Granek, J Oncol Pract. 2013



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Lack of Experience, Good Mentorship, Tools and/or Training



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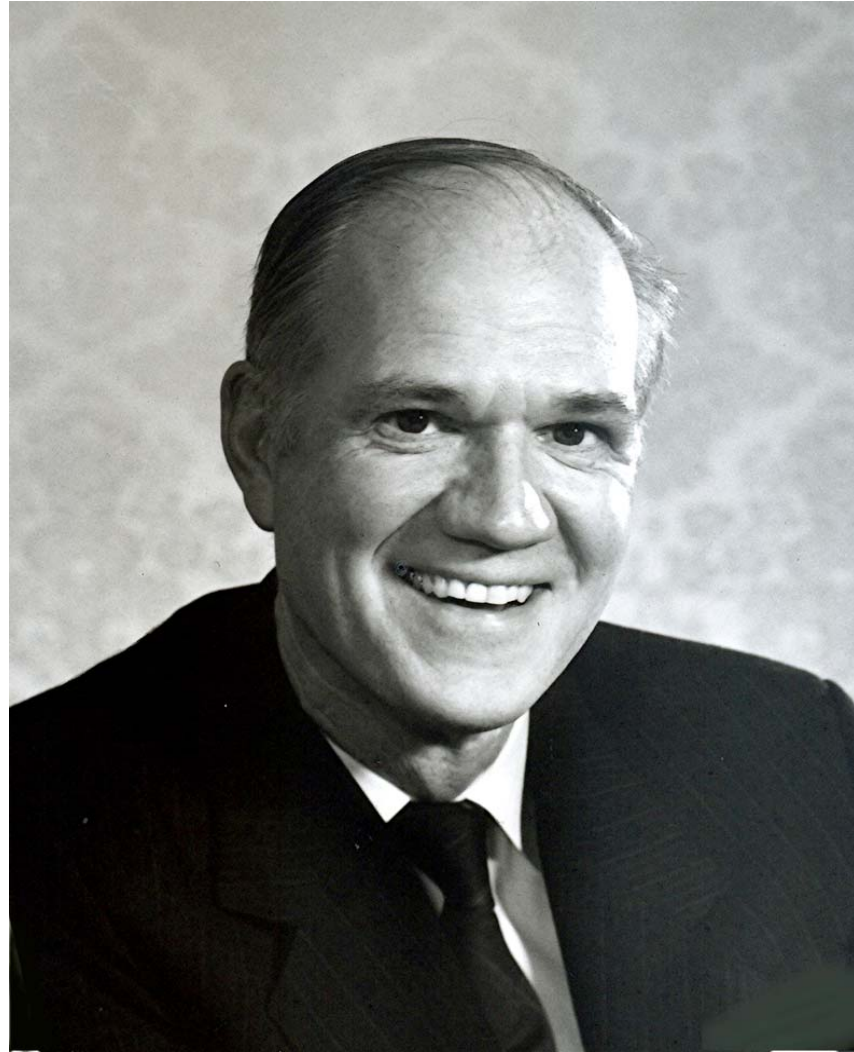


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John F. Seely 1936 - 2009

“I try to make every interaction I have with a patient or their family healing in some way”



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Robert A. Buckman 1948 - 2011

SPIKES

- SETTING:
- PERCEPTION:
- INVITATION:
- KNOWLEDGE:
- EMPATHY:
- SUMMARY”



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Speak Up
Start the conversation
about end-of-life care

JUST ASK:

Talking to patients and families
about Advance Care Planning



<http://www.advancecareplanning.ca>



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“I didn’t expect him to die so soon. I got the feeling the doctors weren’t entirely honest with us about his condition. My husband resisted talking about dying and after 40 years of marriage I feel he let me down by not opening up and I guess I let him down for not knowing how to talk about some of the things that I needed to discuss. It would have been nice closure if things had been different in the end. I can never get that time back.”–

Wife of participant in end-of-life study

Heyland, Open Med, 2009



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Questions



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