Improving Quality of Life in Patients with Advanced Cancers

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Overview

• End-of-life (EOL) care today
• Barriers to EOL discussions
• Evidence that EOL discussions improve care and outcomes.
• Approaches to talking with patients
• Early efforts to scale discussions
Necessary Collusion: Prognostic Communication With Advanced Cancer Patients

Paul E. Heit

INTRODUCTION

As a young oncologist, I have been troubled by the practice in which the benefits and risks of treatments for cancer are communicated to patients in ways that do not fully disclose the available information. This study was designed to explore the perceptions of oncologists and patients regarding the information that is provided to patients with advanced cancer.

HITTING YOU OVER THE HEAD: ONCOLOGISTS’ DISCLOSURE OF PROGNOSIS TO ADVANCED CANCER PATIENTS

ELISA J. GORDON, CHRISTOPHER K. PAPPAS

ABSTRACT

The disclosure of prognostic information to patients is a decision-making process that is often controversial. This study investigated the perceptions of oncologists and patients regarding the information that is provided to patients with advanced cancer.

Collusion in doctor-patient communication about imminent death: an ethnographic study

Anne-Mei The, Tony Hak, Gerard Koever, Gerrit van der Wal

Abstract

Objective To discover and explore the factors that result in "false optimism about recovery" observed in patients with small cell lung cancer. Design A qualitative observational (ethnographic) study in two stages over four years.

Setting Lung diseases ward and outpatient clinic in a university hospital in the Netherlands.

Participants 35 patients with small cell lung cancer.

Results False optimism about recovery usually developed during the first course of chemotherapy and was most prevalent when the cancer could no longer be seen in the x-ray pictures. This optimism tended to wane as the tumour recurred, but it could develop again, even though it was not severe, during further courses of chemotherapy.

Introduction

Almost all patients with cancer want to know their prognosis and most patients also want to be informed about the chance that they will be cured. This does not imply that these patients want to hear the really bad news about their condition. Many patients, when they fear that their prognosis is rather poor, do not ask for precise information and do not hear it if it is provided by the doctor. Our study started from the observation that, after their first course of chemotherapy, virtually all patients with small cell lung cancer in a university hospital programme showed a "false optimism" about their recovery, in the sense that the patients' interpretations of their prognosis were...
Patients living with serious illness have many priorities in addition to living longer.

– Symptom management and quality of life
– Sense of control and completion
– Strengthening of relationships

Singer JAMA 1999; Steinhauser JAMA 2000; Heyland Palliative Medicine 2015
Gap Between What Patients Want and What They Get

Most people want to be at home and prefer comfort-focused care at the end of life, but often not the reality.

- 86% Medicare beneficiaries want to spend final days at home
- 25-39% die in an acute care hospital
- 70% are hospitalized in the last 90 days
- 29% receive intensive, hospital-based care in the last 30 days
- Many experience care transitions and very short hospice stays

Barnato, Medical Care 2007; Teno JAMA 2013; Silveira, NEJM 2010
Bitter Pill or Better Medicine?

• **Question 1**: Is there an association between EOL discussions and patients’ mental health and/or psychiatric disorders?

• **Question 2**: Are EOL discussions associated with less aggressive medical care near death?
Coping with Cancer: Study Schema

- **Patient Death**
  - Patient Care
    - Ventilation
    - Resuscitation
    - ICU
    - Hospice
  - Caregiver Bereavement Outcomes
    - Mental Health
    - Quality of Life
    - SF-36
    - Regret
    - Preparation for Death

- **EOL Discussion**

- **Patient Quality of Life**

<table>
<thead>
<tr>
<th>Enrollment</th>
<th>Last Week of Life</th>
<th>Bereavement Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=638</td>
<td>n=332</td>
<td>n=202</td>
</tr>
</tbody>
</table>
### EOL Discussions: No Evidence of Distress

**Table 2. Associations Between Advanced Cancer Patients’ End-of-Life Discussions, Mental Health, Terminal Illness Acceptance, Treatment Preferences, and Planning**

<table>
<thead>
<tr>
<th>Mental disorders</th>
<th>Total Sample (N = 332)</th>
<th>Yes (n = 123)</th>
<th>No (n = 209)</th>
<th>Adjusted OR (95% Confidence Interval)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major depressive disorder</td>
<td>22 (6.7)</td>
<td>10 (8.3)</td>
<td>12 (5.8)</td>
<td>1.33 (0.54-3.32)</td>
<td>.53</td>
</tr>
<tr>
<td>Major depressive disorder-Endicott</td>
<td>20 (6.1)</td>
<td>7 (5.8)</td>
<td>13 (6.3)</td>
<td>0.73 (0.26-2.06)</td>
<td>.56</td>
</tr>
<tr>
<td>Generalized anxiety disorder</td>
<td>7 (2.1)</td>
<td>4 (3.3)</td>
<td>3 (1.4)</td>
<td>2.50 (0.51-12.1)</td>
<td>.26</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>10 (3.1)</td>
<td>2 (1.7)</td>
<td>8 (3.9)</td>
<td>0.55 (0.16-1.90)</td>
<td>.34</td>
</tr>
<tr>
<td>Posttraumatic stress disorder</td>
<td>9 (2.7)</td>
<td>4 (3.3)</td>
<td>5 (2.4)</td>
<td>0.95 (0.24-3.75)</td>
<td>.94</td>
</tr>
<tr>
<td>Any mental disorder</td>
<td>33 (10.2)</td>
<td>11 (9.2)</td>
<td>22 (10.7)</td>
<td>0.73 (0.35-1.55)</td>
<td>.41</td>
</tr>
</tbody>
</table>

**McGill psychological subscale, adjusted least square means (SE)**

<table>
<thead>
<tr>
<th>Psychological subscale</th>
<th>Depressed (7.4 (2.9))</th>
<th>Nervous or worried (6.9 (3.2))</th>
<th>Sad (7.2 (3.0))</th>
<th>Terrified (7.2 (3.1))</th>
<th>Any psychological distress (5.4 (0.1))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressed</td>
<td>7.4 (2.9)</td>
<td>6.9 (3.2)</td>
<td>7.2 (3.0)</td>
<td>7.2 (3.1)</td>
<td>5.4 (0.1)</td>
</tr>
<tr>
<td>Nervous or worried</td>
<td>7.3 (0.2)</td>
<td>6.5 (0.3)</td>
<td>7.3 (0.2)</td>
<td>7.1 (0.3)</td>
<td>5.3 (0.2)</td>
</tr>
<tr>
<td>Sad</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Terrified</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any psychological distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Wright AA, et al., JAMA, 2008*
### EOL Discussions: Preferences and Planning

#### Table 2. Associations Between Advanced Cancer Patients’ End-of-Life Discussions, Mental Health, Terminal Illness Acceptance, Treatment Preferences, and Planning

<table>
<thead>
<tr>
<th>Acceptance, preferences, and planning</th>
<th>Total Sample (N = 332)</th>
<th>Yes (n = 123)</th>
<th>No (n = 209)</th>
<th>Adjusted OR (95% Confidence Interval)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepts illness is terminal</td>
<td>125 (37.7)</td>
<td>65 (52.9)</td>
<td>60 (28.7)</td>
<td>2.19 (1.40-3.43)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Wants to know life expectancy</td>
<td>242 (72.9)</td>
<td>103 (83.7)</td>
<td>139 (66.5)</td>
<td>2.40 (1.43-4.04)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Values comfort over life-extension</td>
<td>245 (73.8)</td>
<td>105 (85.4)</td>
<td>140 (70.0)</td>
<td>2.63 (1.54-4.49)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Against death in ICU</td>
<td>118 (35.5)</td>
<td>60 (48.8)</td>
<td>58 (27.8)</td>
<td>2.13 (1.35-3.37)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Completed DNR order</td>
<td>134 (41.1)</td>
<td>75 (63.0)</td>
<td>59 (28.5)</td>
<td>3.12 (1.98-4.90)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Completed living will, durable power of attorney, or health care proxy</td>
<td>181 (55.2)</td>
<td>86 (71.7)</td>
<td>95 (46.1)</td>
<td>1.96 (1.25-3.07)</td>
<td>.003</td>
</tr>
</tbody>
</table>

Abbreviation: DNR, do not resuscitate; ICU, intensive care unit; OR, odds ratio.

Wright AA, et al., JAMA, 2008
## EOL Discussions: Less Aggressive Care

### Table 3. Medical Care Received in the Last Week of Life by End-of-Life Discussion

<table>
<thead>
<tr>
<th>Medical care received in the last week</th>
<th>Total (N=332)</th>
<th>No. (%)</th>
<th>Adjusted OR (95% Confidence Interval)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>332</td>
<td>209 (63.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>End-of-Life Discussion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>123 (37.0)</td>
<td>26 (12.4)</td>
<td>0.35 (0.14-0.90)</td>
<td>.02</td>
</tr>
<tr>
<td>No</td>
<td>209 (63.0)</td>
<td>5 (1.6)</td>
<td>0.26 (0.08-0.83)</td>
<td>.02</td>
</tr>
<tr>
<td>ICU admission</td>
<td>31 (9.3)</td>
<td>26 (12.4)</td>
<td>0.16 (0.03-0.80)</td>
<td>.02</td>
</tr>
<tr>
<td>Ventilator use</td>
<td>25 (7.5)</td>
<td>23 (11.0)</td>
<td>0.36 (0.13-1.03)</td>
<td>.08</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>15 (4.5)</td>
<td>14 (6.7)</td>
<td>1.30 (0.55-3.10)</td>
<td>.52</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>19 (5.7)</td>
<td>14 (6.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding tube</td>
<td>26 (7.9)</td>
<td>15 (7.3)</td>
<td>1.65 (1.04-2.63)</td>
<td>.03</td>
</tr>
<tr>
<td>Outpatient hospice used</td>
<td>213 (64.4)</td>
<td>120 (57.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outpatient hospice ≥1 wk</td>
<td>173 (52.3)</td>
<td>93 (44.5)</td>
<td>1.50 (0.91-2.48)</td>
<td>.10</td>
</tr>
</tbody>
</table>

Abbreviation: ICU, intensive care unit; OR, odds ratio.

The propensity-score weighted sample was used for these analyses. Logistic regression models were also adjusted for patients’ treatment preferences, desire for prognostic information, and acceptance of terminal illness.

Wright AA, et al., JAMA, 2008
Timing of Hospice Referral Matters

Figure. Relationship Between Quality of Life and End-of-Life Care

Results are adjusted for illness severity, as measured by Karnofsky score and survival. Caregivers were asked, “In your opinion, how would you rate the overall quality of the patient’s death or last week of life?” Response items were arranged on a Likert scale from 0 “worst possible” to 10 “best possible.” The hospice statistical scores were $F=4.04, P<.001$. Interventions included ventilation, resuscitation, chemotherapy, or feeding tube ($F=3.61, P=.01$). Error bars represent 95% confidence intervals.

Wright AA, et al., JAMA, 2008
Higher Health Costs Associated with Worse Patient Quality of Life Near Death

**Figure.** Association between cost and quality of death in the final week of life (adjusted $P=0.006$). Age, sex, education status, survival time, race/ethnicity, and source of report were controlled for in the adjusted analysis of per capita cost predicting quality of death in the deceased cohort ($n=316$).

Cascading Effects of End-of-Life Care

• Bereaved caregivers of patients who received aggressive care:
  – Worse quality of life (SF36: self-reported health)
  – Less prepared for death
  – More regret
  – Higher odds SCID-criteria for MDD
Patients’ EOL Experiences by Place of Death

Terminal Hospitalizations: Increased Odds of Psychiatric Disorders in Bereaved Caregivers

```
Table 4. Bereaved Caregivers’ Mental Health Outcomes by Patients’ Place of Death

<table>
<thead>
<tr>
<th>Bereaved Caregivers’ Mental Health Outcomes</th>
<th>Patients’ Place of Death*</th>
<th>Intensive Care Unit</th>
<th>Hospital</th>
<th>Home Without Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>AOR</td>
<td>95% CI</td>
<td>P†</td>
</tr>
<tr>
<td></td>
<td></td>
<td>AOR</td>
<td>95% CI</td>
<td>P†</td>
</tr>
<tr>
<td>PTSD‡</td>
<td>10</td>
<td>5.00</td>
<td>1.26 to 19.91</td>
<td>.02</td>
</tr>
<tr>
<td>GAD§</td>
<td>4</td>
<td>5.35</td>
<td>0.69 to 41.51</td>
<td>.11</td>
</tr>
<tr>
<td>PD</td>
<td></td>
<td></td>
<td>9</td>
<td>0.60</td>
</tr>
<tr>
<td>MDD¶</td>
<td>17</td>
<td>3.49</td>
<td>0.86 to 14.22</td>
<td>.08</td>
</tr>
<tr>
<td>PGD#</td>
<td>15</td>
<td>5.24</td>
<td>0.62 to 44.36</td>
<td>.13</td>
</tr>
</tbody>
</table>
```
Intensive, Hospital-Based Care is Often Harmful

• For patients:
  – Lower quality of life
  – Greater physical and psychological distress

• For bereaved caregivers:
  – More major depression
  – More PTSD
  – More regret
  – Worse quality of life
Conversations are Infrequent, Late, and Limited

- **Infrequent**
  - <1/3 of patients with end-stage diagnoses reported end-of-life (EOL) discussion with clinicians

- **Late**
  - In patients with advanced cancer, first EOL discussion 33 days before death
  - 55% of initial EOL discussions occurred in hospital

- **Limited**
  - Conversations often fail to address key elements

Heyland DK Open Med 2009; Mack AIM 2012; Wright 2008
Little Improvement Over Time

Figure 1. Adjusted Yearly Percentages of Advance Care Planning (ACP) and Subtypes Over Time

Narang, JAMA Oncology, 2015
**Little Improvement Over Time**

Table 2. Associations Between ACP and EOL Treatment Intensity

<table>
<thead>
<tr>
<th>ACP Subtype</th>
<th>Certain Treatments Limited or Withheld (n = 1316)</th>
<th>All Care Possible Given (n = 204)</th>
<th>Terminal Hospitalizations (n = 597)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion of EOL care preferences</td>
<td>1.93 (1.53-3.14)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0.58 (0.36-0.92)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>0.83 (0.63-1.08)</td>
</tr>
<tr>
<td>Living will</td>
<td>2.51 (1.53-4.11)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>0.49 (0.29-0.84)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0.93 (0.69-1.25)</td>
</tr>
<tr>
<td>Durable power of attorney</td>
<td>1.52 (0.78-2.66)</td>
<td>0.68 (0.41-1.10)</td>
<td>0.70 (0.52-0.94)&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Abbreviations: ACP, advance care planning; EOL, end of life.

* Multivariable models adjusted for age, sex, race, ethnicity, education level, marital status, religion, importance of religion to decedent, veteran status, whether patient lived in nursing home, time from diagnosis to death, comorbidities, geographic region, year of death, relationship of the proxy to the decedent, and other forms of ACP.

<sup>b</sup> P < .01.
<sup>c</sup> P < .05.
<sup>d</sup> P < .001.
End-of-life Cancer Care Varies Widely

Hospital days during the last month of life
End-of-Life Care: Insensitive to Patient Preferences?

Physician Characteristics Strongly Predict Hospice Enrollment

EXHIBIT 1
Variation In The Percentage Of A Physician’s Patients With Poor-Prognosis Cancer Enrolled In Hospice Before Death, 2006-11

Percent of patients in hospice

0-5
6-10
11-15
16-20
21-25
26-30
31-35
36-40
41-45
46-50
51-55
56-60
61-65
66-70
71-75
76-80
81-85
86-90
91-95
96-100

Percent of physicians in cohort

Obermoyer Z, Health Affairs, 2015.
### Exhibit 2

#### Associations Between Patient And Physician Characteristics And Enrollment In Hospice By Patients With A Poor-Prognosis Cancer Diagnosis Who Died In 2006-11

<table>
<thead>
<tr>
<th></th>
<th>Odds ratio</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1.02</td>
<td>(1.02, 1.02)</td>
</tr>
<tr>
<td>Male sex</td>
<td>0.77</td>
<td>(0.75, 0.78)</td>
</tr>
<tr>
<td>White race</td>
<td>1.42</td>
<td>(1.38, 1.47)</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>1.03</td>
<td>(1.03, 1.04)</td>
</tr>
<tr>
<td><strong>Physician Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facility for-profit status</td>
<td>0.93</td>
<td>(0.90, 0.96)</td>
</tr>
<tr>
<td>Physician specialty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical oncology</td>
<td>1.00</td>
<td>—</td>
</tr>
<tr>
<td>Internal or family medicine</td>
<td>0.90</td>
<td>(0.88, 0.93)</td>
</tr>
<tr>
<td>Medical subspecialty</td>
<td>0.77</td>
<td>(0.75, 0.80)</td>
</tr>
<tr>
<td>Other</td>
<td>0.96</td>
<td>(0.87, 1.05)</td>
</tr>
<tr>
<td>Radiation oncology</td>
<td>0.97</td>
<td>(0.94, 1.00)</td>
</tr>
<tr>
<td>Surgery (general or subspecialty)</td>
<td>0.72</td>
<td>(0.69, 0.75)</td>
</tr>
<tr>
<td>Fraction of patients with poor-prognosis cancer enrolled in hospice</td>
<td>2.67</td>
<td>(2.53, 2.82)</td>
</tr>
<tr>
<td><strong>Year at the time of enrollment or death</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>1.00</td>
<td>—</td>
</tr>
<tr>
<td>2008</td>
<td>1.01</td>
<td>(0.98, 1.04)</td>
</tr>
<tr>
<td>2009</td>
<td>1.06</td>
<td>(1.03, 1.10)</td>
</tr>
<tr>
<td>2010</td>
<td>1.11</td>
<td>(1.07, 1.14)</td>
</tr>
<tr>
<td>2011</td>
<td>1.04</td>
<td>(1.01, 1.07)</td>
</tr>
</tbody>
</table>

Obermoyer Z, Health Affairs, 2015.
# Physician Characteristics Strongly Predict Hospice Enrollment

## Exhibit 3

### Simulated Impacts Of Patient And Physician Characteristics On Enrollment In Hospice By Patients With A Poor-Prognosis Cancer Diagnosis Who Died In 2006–11

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Lowest decile of characteristic or absence of risk factor</th>
<th>Highest decile of characteristic or presence of risk factor</th>
<th>Change in likelihood (%)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENT</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male sex</td>
<td>0.69</td>
<td>0.64</td>
<td>−8.39</td>
<td>(–8.40, –8.38)</td>
</tr>
<tr>
<td>White race</td>
<td>0.59</td>
<td>0.67</td>
<td>13.88</td>
<td>(13.86, 13.89)</td>
</tr>
<tr>
<td>Age</td>
<td>0.62</td>
<td>0.71</td>
<td>15.95</td>
<td>(15.93, 15.98)</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>0.62</td>
<td>0.71</td>
<td>15.33</td>
<td>(15.31, 15.36)</td>
</tr>
<tr>
<td><strong>PHYSICIAN</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facility profit status</td>
<td>0.66</td>
<td>0.65</td>
<td>−2.47</td>
<td>(–2.48, –2.47)</td>
</tr>
<tr>
<td>Fraction of patients with poor-prognosis cancer enrolled in hospice</td>
<td>0.58</td>
<td>0.73</td>
<td>26.79</td>
<td>(26.75, 26.82)</td>
</tr>
</tbody>
</table>

Obermoyer Z, Health Affairs, 2015.
Most people want to be at home and prefer comfort-focused care at the end of life, but often not the reality.
How to bridge the gap between what patients want and what they get?

Ask patients about their values and priorities
### Table. Communication Tips

<table>
<thead>
<tr>
<th>Do</th>
<th>Don’t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give a direct, honest prognosis\textsuperscript{99,101}</td>
<td>Avoid responding to a patient request for information about prognosis\textsuperscript{102}</td>
</tr>
<tr>
<td>Provide prognostic information as a range; acknowledge uncertainty, eg, “we think you have weeks to a small number of months, but it could be shorter or longer”\textsuperscript{103}</td>
<td>Provide vague, eg, “incurable” or overly specific information, eg, “you have 6 months”</td>
</tr>
<tr>
<td>Allow silence\textsuperscript{104}</td>
<td>Talk more than half the time\textsuperscript{104}</td>
</tr>
<tr>
<td>Acknowledge and explore emotions\textsuperscript{105}</td>
<td>Provide factual information in response to strong emotions</td>
</tr>
<tr>
<td>Focus on the patient’s quality of life, goals, fears, and concerns\textsuperscript{33}</td>
<td>Focus on medical procedures\textsuperscript{106}</td>
</tr>
</tbody>
</table>

Bernack RE, et al. JAMA Internal Medicine 2014
Serious Illness Conversation Guide

CONVERSATION GUIDE

Understanding
What is your understanding now of where you are with your illness?

Information preferences
How much information about what is likely to be ahead with your illness would you like from me?

For example:
Some patients like to know about time, others like to know what to expect, others like to know both.

Prognosis
Share prognosis, tailored to information preferences

Goals
If your health situation worsens, what are your most important goals?

Fears / Worries
What are your biggest fears and worries about the future with your health?

Function
What abilities are so critical to your life that you can’t imagine living without them?

Trade-offs
If you become sicker, how much are you willing to go through for the possibility of gaining more time?

Family
How much does your family know about your priorities and wishes?
Set up the conversation

Setting up the conversation builds trust, helps patients feel in control, and allows the conversation to begin gently, without scaring the patient.

- Introduce the idea:
  - “I’d like to talk about what is ahead with your illness and do something in advance so that I can make sure we provide you with the care you want.”

- Ask permission:
  - “Is this ok?”

- Introduce the benefits:
  - “The goal is to make sure that I have all of the information I need about what matters most to you so I can provide you with the care you want, and so I can best support your family if they ever have to make decisions for you.”

Prognosis

“I want to share with you my understanding of where things are with your illness...”

1. Time-based prognosis:
   – “I wish we were not in this situation, but I’m worried that time may be as short as ___. I’m worried that, in terms of time, we may be talking about months to a year. Of course, we don’t know for sure, and it could be longer or shorter.”

2. Functional prognosis:
   – “I hope that this is not the case, but I’m worried that things are likely to get more difficult.

3. Unpredictable prognosis:
   – “It can be difficult to predict what will happen with your disease. Some people live well for a long time, but others can get very sick very quickly (to the point that they might die.)”

Slide courtesy of Bernacki RE, et al.
Bernacki RE, et al. JAMA Internal Medicine 2014
Serious Illness Communication Project

Cluster-randomized controlled trial in outpatient oncology

• 90 oncology clinicians (MDs, NPs, and PAs) volunteered and enrolled (72% participation rate)
• 278 patients with advanced cancer enrolled and randomized
  - 131 patients died

Conversation Outcomes

• More conversations (92.7% vs 74.7% p=0.006)
• Earlier conversations (147 days vs 62 days p=0.003)
• More accessible in EHR (59.4% vs 10.2% p=0.001)

Slide courtesy of Bernacki RE, et al.; ClinicalTrials.gov: NCT01786811
Significant Improvements in Conversations

Significant increase documentation about:

- Values and goals (85% vs 40%, p=0.0001)
- EOL care planning (85% vs. 55%, p=0.009)
- Prognosis (85% vs 30% p=0.001)

Two weeks post conversation:

- Proportion of patients with **moderate/severe anxiety** in intervention group **half** that of control (4.8% vs 11%, p=0.05)
- Proportion of patients with **moderate/severe depression** in intervention group **half** that of control (10.9% vs. 21.8%, p=0.03)

Slide courtesy of Bernacki RE, et al.; ClinicalTrials.gov: NCT01786811
## Patients Report Positive Experiences

<table>
<thead>
<tr>
<th>Practical planning</th>
<th>“Making changes to my will. Plan my funeral.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication with family</td>
<td>“More realistic in my approach with family and friends about my prognosis.”</td>
</tr>
<tr>
<td>End-of-life care planning</td>
<td>“Made a complete list of all my last wishes, such as when I can no longer go to the bathroom myself I want hospice house care.”</td>
</tr>
<tr>
<td>Well-being</td>
<td>“I am doing the same stuff as before, just feeling less anxious about the future (hope for the best, prepare for the worst).”</td>
</tr>
<tr>
<td>Values, goals, and priorities</td>
<td>“I have started to think about what my priorities are in terms of quality of life.”</td>
</tr>
<tr>
<td>Therapeutic relationship</td>
<td>“Mostly the conversation brought us closer (Dr. X).”</td>
</tr>
</tbody>
</table>

Preliminary Qualitative Analysis

Slide courtesy of Bernacki RE, et al.; ClinicalTrials.gov: NCT01786811
Bolster Physician Communication
Activate Patients and Physicians

Next, help us to understand what type of information is important to you as a patient.

How much information do you want to know about your cancer?

- I don't want to know any details about my cancer
- I want to know some details about my cancer
- I want to know as much as possible about my cancer

What are your preferences for how decisions about your medical care are made?

- I prefer my doctors to make all of my medical decisions
- I prefer to share decisions equally with my doctors
- I prefer to make all of my medical decisions myself

What are your preferences for the role you want your family to play in decisions about your medical care?

- I prefer my family to make decisions with little or no input from me
- I prefer to share decisions equally with my family
- I prefer to make all decisions with little or no input from family

Your doctor can often provide an estimate of how long people with cancers like yours are likely to live, on average (prognosis). Would you want your doctor to share this information with you?

- Yes
- Not now → when do you think you might want to know? _______________
- Never
- I don't know

Do you worry about getting too much or too little cancer treatment or care (chemotherapy, tests, procedures, etc.)?

- I'm worried that I won't get enough cancer treatment
- I expect to get just the right amount of cancer treatment
- I'm worried that I'll get too much cancer treatment

Keating NL, Wright AA; ClinicalTrials.gov: NCT03392090
Automate with EHR Triggers (Default)

Halpern SD, ClinicalTrials.gov: NCT02100566
Behavioral Economics: Multi-Component Physician Intervention

Figure 2. Adjusted Rates of Antibiotic Prescribing at Primary Care Office Visits for Antibiotic-Inappropriate Acute Respiratory Tract Infections Over Time

A. Accountable justification
B. Peer comparison
C. Suggested alternatives

Take Homes

• End-of-life care is not yet patient-centered

• End-of-life discussions are key:
  – Enhanced goal-concordant care
  – Improved quality of life
  – Reduced suffering
  – Better patient and family coping
  – \downarrow Non-beneficial care and costs

• Early efforts to scale end-of-life discussions

• There’s still a lot to be done
Take Homes

• You have a critical role in improving patient care by improving conversations
  – Identify patients at high risk who would benefit most from serious illness conversations.
  – Initiate conversations using best practices.
  – Document the discussions in a retrievable location in the EHR so all providers can access.
  – Set an example of high-quality communication for colleagues and trainees.
Questions?
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But we can’t provide this care to all patients with serious illness

- We do not have enough palliative care physicians to provide access to palliative care for all patients with serious illness
- We need scalable interventions targeted at generalist (non-palliative care) physicians and other clinicians to assure universal access to key elements of palliative care
Health Care Transitions at the End-of-Life and Inpatient Hospice Referrals Rising

Wright AA, et al., J Clin Oncol, 2014
Patients’ Expectations about Effects of Chemotherapy for Advanced Cancer

Increasing Hospice Use, Decreasing Terminal Hospitalizations, But More Medical Care Near Death

Wright AA, et al., J Clin Oncol, 2014
Dying Patients Spend 1 Week of their Last Month of Life in the Hospital on average
Assess illness understanding and information preferences

Illness understanding provides an indication of how realistic the patient is about prognosis and provides the clinician information about how much gentle pushing is needed to prepare the patient for what is ahead

• “What is your understanding now of where you are with your illness?”

Information preferences guide clinician in titrating information to patient preferences, and helps clinicians feel confident in moving forward with providing prognostic information

• “How much information about what is likely to be ahead would you like from me?”

Slide courtesy of Bernacki RE, et al.