Prognostic awareness in patients with advanced cancer

Dr Martin Loučka
Center for Palliative Care, Prague
Surgeons use scalpel. Palliative care clinicians use communication.
The Impact of Patients’ Awareness of Disease Status on Treatment Preferences and Quality of Life among Patients with Metastatic Cancer: A Systematic Review from 1997–2014

Catherine Scott Finlayson, MS, RN, OCN, Yu Ting Chen, BS, RN, and Mei R. Fu, PhD, RN, ACNS-BC, FAAN

44% - 77% unaware of their prognosis
Conceptualizing prognostic awareness in advanced cancer: A systematic review

Allison J Applebaum¹, Elissa A Kolva², Julia R Kulikowski¹, Jordana D Jacobs¹, Antonio DeRosa¹, Wendy G Lichtenthal¹, Megan E Olden³, Barry Rosenfeld² and William Breitbart¹
Conceptualizing prognostic awareness in advanced cancer: A systematic review

- level of accurate prognostic awareness

9 - 73.5 %

- various assessment methods
Maybe patients do not want to know?
Preference to know the prognosis varied between **67.6 %** - **80.7 %**

(Ireland) (Flanders)
Experiences and Attitudes of Patients With Terminal Cancer and Their Family Caregivers Toward the Disclosure of Terminal Illness

Young Ho Yun, Yong Chol Kwon, Myung Kyung Lee, Woo Jin Lee, Kyung Hae Jung, Young Rok Do, Samyong Kim, Dae Seog Heo, Jong Soo Choi, and Sang Yoon Park

ABSTRACT

Purpose
We investigated the experiences of cancer patients and their family caregivers who became aware that the cancer was terminal, how they became aware, and how they felt about disclosure of the information.

Patients and Methods
In this cohort study, we administered questionnaires to 619 consecutive patients determined by physicians to be terminally ill and to their family caregivers.
- 58% of patients and 83.4% of caregivers aware of prognosis
- 29% guessed the prognosis from their worsening status
- 78.6% of patients and 69.6% of relatives preferred to be informed of patient’s terminal status
- Patients informed by their physician or family member
  - better quality of life than those who guessed it
  - fewer symptoms and less emotional distress
Patients’ Expectations about Effects of Chemotherapy for Advanced Cancer

Jane C. Weeks, M.D., Paul J. Catalano, Sc.D., Angel Cronin, M.S., Matthew D. Finkelman, Ph.D., Jennifer W. Mack, M.D., M.P.H., Nancy L. Keating, M.D., M.P.H., and Deborah Schrag, M.D., M.P.H.

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Cancer Care Outcomes Research and Surveillance (CanCORS)

- 1193 patients
- IV. stage colorectal or lung cancer

- Aim: to assess patients' expectations that chemotherapy can completely cure their cancer
“After talking with your doctors about chemotherapy, how likely did you think it was that chemotherapy would . . . help you live longer, cure your cancer, or help you with problems you were having because of your cancer?”

Response:
“very likely,”
“somewhat likely,”
“a little likely,”
“not at all likely,”
“don’t know.”
“After talking with your doctors about chemotherapy, how likely did you think it was that chemotherapy would . . . help you live longer, cure your cancer, or help you with problems you were having because of your cancer?”

Response:
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“a little likely,”
“not at all likely,”
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Cancer Care Outcomes Research and Surveillance (CanCORS)

69 % lung ca.
81 % col.ca.

**Figure 1.** Responses to Questions about the Likelihood That Chemotherapy Will Have an Effect, According to the Type of Effect and Diagnosis.

Shown are the responses of patients with advanced lung or colorectal cancer to questions regarding whether chemotherapy will cure their disease (Panel A), extend their life (Panel B), or provide relief of symptoms (Panel C).
Patient Beliefs That Chemotherapy May Be Curative and Care Received at the End of Life Among Patients With Metastatic Lung and Colorectal Cancer

Jennifer W. Mack, MD, MPH\textsuperscript{1,2}; Anne Walling, MD, PhD\textsuperscript{3,4}; Sydney Dy, MD\textsuperscript{5}; Anna Liza M. Antonio, MS\textsuperscript{3,4,6}; John Adams, PhD\textsuperscript{3,4}; Nancy L. Keating, MD, MPH\textsuperscript{7,8}; and Diana Tisnado, PhD\textsuperscript{9}

722 patients, stage IV lung or colorectal cancer

33 % answered correctly about the aim of CH

- no difference in chemo in the last month before death
  (OR, 1.32; 95%, CI 0.84-2.09; P.23)

- more likely to be referred to hospice care:
  49.2 % vs. 28.4 % (OR, 1.97; 95% CI 1.37-2.82, P < .001)
Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public

Maurice L Slevin, Linda Stubbs, Hilary J Plant, Peter Wilson, Walter M Gregory, P Joanne Armes, Susan M M Downer

TABLE I—Median scores (representing minimal benefit to make two hypothetical treatments acceptable in three circumstances) for controls, cancer nurses, general practitioners, cancer doctors, and patients with cancer

<table>
<thead>
<tr>
<th>Subject group</th>
<th>Controls (n=100)</th>
<th>Cancer nurses (n=303)</th>
<th>General practitioners (n=790)</th>
<th>Cancer doctors (n=148)</th>
<th>Patients (n=100)</th>
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<tbody>
<tr>
<td>Intensive treatment:</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Chance of cure (%)</td>
<td>50</td>
<td>50</td>
<td>25</td>
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<td>1</td>
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<tr>
<td>Prolonging life (months)</td>
<td>24-60</td>
<td>24</td>
<td>24</td>
<td>12</td>
<td>12</td>
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<tr>
<td>Relief of symptoms (%)</td>
<td>75</td>
<td>50</td>
<td>75</td>
<td>50</td>
<td>10</td>
</tr>
<tr>
<td>Mild treatment:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chance of cure (%)</td>
<td>25</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Prolonging life (months)</td>
<td>18</td>
<td>12</td>
<td>12</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Relief of symptoms (%)</td>
<td>50</td>
<td>25</td>
<td>25</td>
<td>25</td>
<td>1</td>
</tr>
</tbody>
</table>
Doctor-to-doctor communication of prognosis in metastatic cancer: a review of letters from medical oncologists to referring doctors

E. B Moth,1 J. Parry,2 M. R Stockler,1,3 P. Beale,1,4 P. Blinman,1,4 S. Della-Fiorentina2 and B. E Kiely1,2 3

1Concord Cancer Centre, Concord Repatriation General Hospital, 2Macarthur Cancer Therapy Centre, Campbelltown Hospital, 3NHMRC Clinical Trials Centre and 4Sydney Medical School, University of Sydney, Sydney, New South Wales, Australia

Received 8 February 2015; accepted 30 March 2015.

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- 1344 letters, 272 patients, median survival 13 months
  - ‘metastatic’ or ‘stage IV’ in 93 % patients
  - ‘palliative’ in 64 %
  - ‘incurable’ in 34 %
  - quantitative estimate of prognosis in 11 %
Less than 2% (3 of 179) of surrogates reported that their beliefs about the patients’ prognoses hinged exclusively on prognostic information provided by physicians.
Aims of the study

- To identify priorities of patients with advanced cancer (How important is PA?)
- Which factors influence PA?
- To assess longitudinal changes in PA
- To assess the differences in PA among patients, family caregivers and physicians
PART I: Systematic review

• MEDLINE, CINAHL, Embase, PsyInfo
• 1990-2017
• adult patients with cancer
• EN, FR, CZ

1. cancer; cancer staging;
2. awareness; health knowledge; attitudes; understanding;
3. prognosis; diagnosis; perception;
Identified records: 26,599
Screened records: 24,204
Assessed abstracts: 2,616
Assessed full-texts: 132
Included studies: 61
PA

- Illness trajectory
- Personality
- Communication
- Health condition
- Psychology
- Demography
- Relatives
# Psychological factors

<table>
<thead>
<tr>
<th>Factors</th>
<th>+</th>
<th>-</th>
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</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>3</td>
<td>8</td>
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<tr>
<td>Depression</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5</td>
<td>8</td>
</tr>
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</table>
## Psychological factors

<table>
<thead>
<tr>
<th>Factors</th>
<th>+</th>
<th>-</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well-being</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Being burden to others</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Refusal of psychological help</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>
Part II

- questionnaire survey in patients with advanced disease and their caregivers
- 40 factors, Likert scale to measure the importance
- PA: do you consider your illness to be rather
  - curable
  - Incurable
- 5 hospitals
- chronic disease + negative surprise question
Stage 1

- 170 patients, 107 relatives, 113 physicians
  - female 50%
  - age 70 (patients), 58 (relatives)
  - 64% cancer dg.
  - 44% patients estimated survival less than 6 months
<table>
<thead>
<tr>
<th></th>
<th>PATIENTS</th>
<th>RELATIVES</th>
<th>PHYSICIANS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain one’s independence in selfcare</td>
<td>4.40</td>
<td>4.16</td>
<td>4.47</td>
</tr>
<tr>
<td>Keep relationships with friends</td>
<td>4.08</td>
<td>4.07</td>
<td>4.03</td>
</tr>
<tr>
<td>Spend as much time as possible with family and friends</td>
<td>4.48</td>
<td>4.59</td>
<td>4.73</td>
</tr>
<tr>
<td>In case of progression spend rest of time home</td>
<td>3.98</td>
<td>4.17</td>
<td>4.24</td>
</tr>
<tr>
<td>Have financial affairs in order</td>
<td>4.02</td>
<td>3.62</td>
<td>3.79</td>
</tr>
<tr>
<td>Believe family and friends are can cope with one’s disease</td>
<td>4.09</td>
<td>3.80</td>
<td>3.97</td>
</tr>
<tr>
<td>Not to be a burden</td>
<td>4.31</td>
<td>3.75</td>
<td>4.02</td>
</tr>
<tr>
<td>Do not depend on help from other people</td>
<td>4.02</td>
<td>3.51</td>
<td>3.79</td>
</tr>
<tr>
<td>Get information from a doctor even if they are bad</td>
<td>4.22</td>
<td>3.83</td>
<td>3.77</td>
</tr>
<tr>
<td>Have enough privacy for conversation with doctor</td>
<td>3.84</td>
<td>4.13</td>
<td>4.26</td>
</tr>
<tr>
<td>Have enough time for talking to doctor</td>
<td>4.07</td>
<td>4.25</td>
<td>4.29</td>
</tr>
<tr>
<td>Be perceived as a whole person, not just a patient</td>
<td>4.24</td>
<td>4.54</td>
<td>4.29</td>
</tr>
<tr>
<td>Well organized health care</td>
<td>4.19</td>
<td>4.21</td>
<td>4.12</td>
</tr>
<tr>
<td>Be hospitalized just in case of emergency</td>
<td>4.18</td>
<td>4.02</td>
<td>3.85</td>
</tr>
<tr>
<td>Have enough information about side effects of cure</td>
<td>4.11</td>
<td>3.86</td>
<td>3.84</td>
</tr>
<tr>
<td>Be free of insomnia</td>
<td>4.11</td>
<td>3.98</td>
<td>4.08</td>
</tr>
<tr>
<td>Be free of pain</td>
<td>4.45</td>
<td>4.65</td>
<td>4.76</td>
</tr>
<tr>
<td>Be free of indigestion</td>
<td>4.23</td>
<td>4.18</td>
<td>4.29</td>
</tr>
<tr>
<td>Having enough energy, no to be tired</td>
<td>4.23</td>
<td>3.86</td>
<td>3.72</td>
</tr>
<tr>
<td>Be free of shortness of breath</td>
<td>4.21</td>
<td>4.40</td>
<td>4.55</td>
</tr>
<tr>
<td>Not to be tied up to a bed</td>
<td>4.34</td>
<td>4.18</td>
<td>3.99</td>
</tr>
<tr>
<td>Keep hope during the illness</td>
<td>4.31</td>
<td>4.28</td>
<td>3.94</td>
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<tr>
<td>Keep optimism during the illness</td>
<td>4.26</td>
<td>4.04</td>
<td>3.76</td>
</tr>
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<td>3.75</td>
<td>-</td>
</tr>
<tr>
<td>Do not depend on help from other people</td>
<td>4.02</td>
<td>3.51</td>
<td>-</td>
</tr>
<tr>
<td>Be useful</td>
<td>3.78</td>
<td>3.12</td>
<td>3.11</td>
</tr>
<tr>
<td><strong>Get information from the doctor even if they are bad</strong></td>
<td><strong>4.22</strong></td>
<td><strong>3.83</strong></td>
<td><strong>3.77</strong></td>
</tr>
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<td>Have enough privacy for conversation with the doctor</td>
<td>3.84</td>
<td>-</td>
<td>4.26</td>
</tr>
<tr>
<td>Have opportunity to contact clergyman</td>
<td>2.17</td>
<td>2.88</td>
<td>3.57</td>
</tr>
<tr>
<td>Be free of pain</td>
<td>4.45</td>
<td>-</td>
<td>4.76</td>
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<td>4.26</td>
<td>-</td>
<td>3.76</td>
</tr>
</tbody>
</table>
Results

- patients thought that their illness is rather
  - curable 53 %
  - incurable 47 %

- relatives‘ perspective:
  - curable 37 %
  - incurable 63 %
Stage 2

- advanced cancer (negative SQ)
- How important is for you to have information about your prognosis?
- PA, QoL, survival estimates by physicians, communication with family, communication about EoL, preference for shared decision making, spirituality, demographics
- „How was it for you?“
Stage 2 – PA measurement

- How would you describe your current health status?
  - relatively healthy
  - I am ill, but it is not too serious
  - My illness is serious, but not life-threatening
  - My illness is very serious and I will most likely die of it.

- How would your family answer to this question?
Stage 2 – PA measurement

- How likely you think is that your cancer will be cured?
  - 0 % ………….. 100 %

- What do you think is the main goal of your current treatment?
  - to cure my illness
  - to extend my life expectancy as much as possible
  - to relieve the symptom burden
Stage 2 – preliminary results

- 3 waves (N1=137, N2=78, N3=46)
- 76 males, 61 females, average age 64.6 years
- reasons for leaving the study
  - Death 40 %
  - Transfer 7 %
  - Lost contact 16 %
  - Loss of interest 30 %
  - Deterioration 7 %
Stage 2 – PA measurement

- How would you describe your current health status?
  - relatively healthy
  - I am ill, but it is not too serious
  - My illness is serious, but not life-threatening
  - My illness is very serious and I will most likely die of it.

- How would your family answer to this question?
Stage 2 – PA measurement

- How would you describe your current health status?
- How likely you think is that your cancer will be cured?
- What do you think is the main goal of your current treatment?
Stage 2 – PA measurement

- How would you describe your current health status? 36.4%

- How likely you think is that your cancer will be cured? 0-30% chance of cure

- What do you think is the main goal of your current treatment? 66.4%
Stage 2 – PA measurement

<table>
<thead>
<tr>
<th>Valid</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
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<tr>
<td>aware</td>
<td>21</td>
<td>15.7</td>
<td>12</td>
<td>15.6</td>
<td>11</td>
<td>24.4</td>
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<tr>
<td>partially aware</td>
<td>78</td>
<td>58.2</td>
<td>38</td>
<td>49.4</td>
<td>21</td>
<td>46.7</td>
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<tr>
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<td>35</td>
<td>26.1</td>
<td>27</td>
<td>35.1</td>
<td>13</td>
<td>28.9</td>
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<tr>
<td>Total</td>
<td>134</td>
<td>100.0</td>
<td>77</td>
<td>100.0</td>
<td>45</td>
<td>100.0</td>
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Future research

- To cover complete trajectory
- Link to communication strategies
- Preferences
- Documentation
- PA in non-cancer patients
Thank you!