## How long do I have to live, doc? Prognostication Tools in Palliative Care A practical approach workshop

Dr. Irene Ying Irene.ying@sunnybrook.ca

Dr. Giovanna Sirianni giovanna.sirianni@sunnybrook.ca @gio\_sirianni

> Dr. Giulia Perri gperri@baycrest.org







## What is your favourite thing about autumn?

Select Live Poll	S Live Poll
<ul> <li>Select this Session</li> </ul>	Saturday, October 26, 2019
	#202-19 - HOW LONG DO I HAVE TO LIVE DOC? PROGNOSTICATION TOOLS IN THE PALLIATIVE CARE APPROACH
	<ul> <li>Provincial North - 2nd</li> <li>Floor</li> <li>1:00 PM - 2:00 PM</li> </ul>
Enter Session PIN	Session PIN 9641
and	

press

# **Disclosure Slides**

Faculty: Dr. Irene Ying, Dr. Giovanna Sirianni, Dr. Giulia Perri

#### **Relationships with commercial interests:**

- Grants/Research Support: None
- Speakers Bureau/Honoraria: None
- Consulting Fees: None
- Other: None

#### No conflicts of interest to declare.

### Mitigating bias: N/A

## Learning Objectives:

Start

Finish

 Identify available tools to help inform prognostication in the palliative care setting.

**3.** Recognize the limitations of prognostication estimates in the clinical setting.

2. Apply the prognostication tools presented to clinical cases and their own practice.

**4.** Learn prognostication pearls from each other.



Any burning questions?

# Getting to know each other.

## Why is the skill of prognostication important to you?

# Importance of Prognostication Perspective of the Clinician:

- 1. Residents and caregivers will ask us.
- 2. Guides goals of care discussions and treatment options.
- 3. Helps connect residents to the right services.

# Importance of Prognostication Perspective of the Resident:

**1**. To prepare for the end of life.

- **2**. To make the most of the life they had left.
- 3. To make medical or health-related decisions.

## Fill in the blank:

# As clinicians, we *tend* to avoid discussions on prognosis because \_\_\_\_\_

## **Barriers to Communicating Prognosis**

- Lack of training on the skill of prognosticating.
- Time consuming.
- Wait to be asked by our resident/SDM.
- Resident/SDM want a precise answer and we can't give it.
- Fear of being wrong.
- Fear of negative impact the patient-doctor relationship.
- Fear of "taking away" hope.
- Fear of doing more harm.

# Defining prognostication.



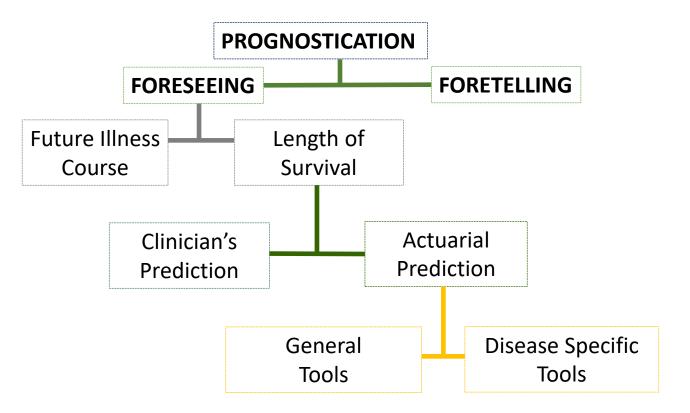
## What do we *really* mean by prognostication?

**Foreseeing:** estimating the likelihood of an outcome due to a medical condition.

## Length of survival

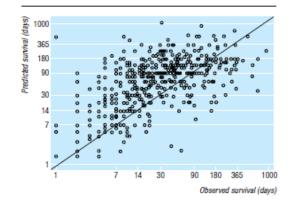
 Future illness course and impact with or without therapies.

**Foretelling**: Communicating to the resident, their families/caregivers/SDM, clinicians.



## **Clinician's Prediction of Survival (CPS)**

Predicted versus observed survival in 468 terminally ill hospice patients.



**Inaccurate:** only 20% of prognoses are accurate.

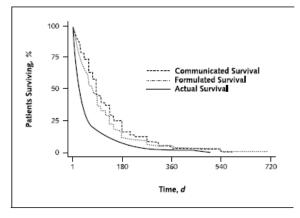


Christakis. BMJ. 2000 Glare. BMJ. 2003 Coventry. Age & Aging. 2005

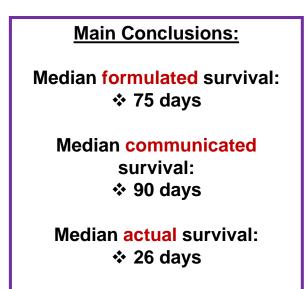
## **Optimistically Optimistic:**

#### Clinician's Prediction of Survival and Prognostic Disclosure

*Figure 2.* Relationship between communicated, formulated, and actual survival.

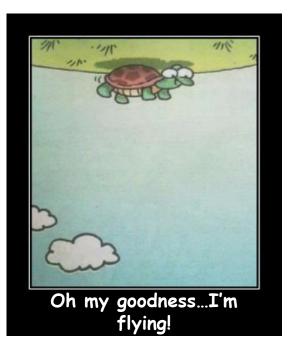


n = 326 hospice patients



## What's really wrong with being optimistic?

**2.5 x:** Life-extending and burdensome interventions



## **No** Palliative Care

Early Palliative Care Integration Works to:

- improves QOL
- satisfaction with care
- better symptom control
- decreases acute care needs
- less burdensome interventions

# Surprise!

Christakis. BMJ. 2000 Glare. BMJ. 2003 Maltoni. JCO 2005

# **Q:** Can we use the "surprise question" to prognosticate?

a.Yes b.No

# **The Surprise Question**



- Who: Dr. Joanne Lynn, MD
- When: In the 90's
- Where: Washington for use in primary care, advanced cancer and dialysis patients
- What: "Would you be surprised if this patient died in the next 12 months?"
- Why: to identify patients with a worse prognosis and appropriateness for palliative care

# The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis

James Downar MDCM MHSc, Russell Goldman MD MPH, Ruxandra Pinto PhD, Marina Englesakis MLIS, Neill K.J. Adhikari MDCM MSc

- 16 studies (11,621 patients)
- Serious illness (both CA and non-CA)

### Main Findings:

- Sensitivity 67%, Specificity 80%
- LR+ 3.4, LR-0.41, PPV 37%, NPV 93%
- High false positive rate
- Better performance in cancer (LR+ 4.2)
- Very poor performance in non-cancer (LR+2.7)

# **Advanced Dementia**

# **Dementia numbers in Canada**

### 25,000

The number of new cases diagnosed every year

## 564,000

Canadians currently living with dementia

## 937,000

Canadians who will be living with dementia in 15 years

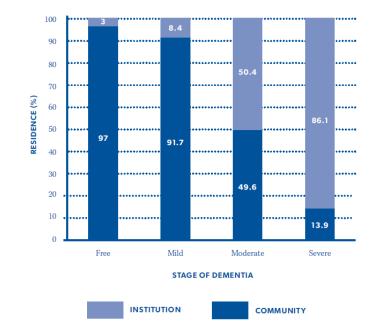
## 1.1 million

Canadians affected directly or indirectly

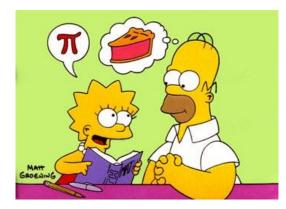
## \$10.4 billion

Annual cost to Canadians to care for those living with dementia

#### Percentages of Residents with Dementia Living in the Community versus in Institutions by Stage of Dementia, Canada



## **Advanced Dementia**

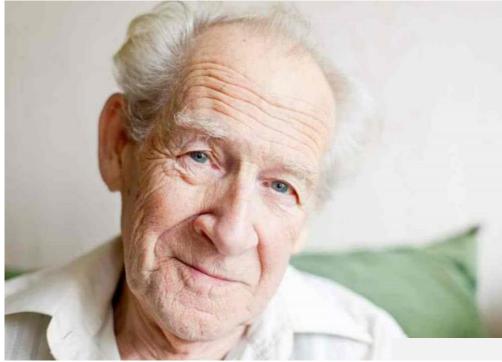


## Common Language: Defining Advanced Dementia

Global Deterioration Scale (GDS), Stage 7:

- Profound memory deficits
- Minimal verbal abilities
- Inability to ambulate independently
- Inability to perform activities of daily living
- Bladder and bowel incontinence

## Meet Mr. K





- 83 yrs
- Widow
- LTC
- Advanced
   Dementia
- HTN
- CHF
- A.fib
- CVA

Function: Mostly in bed. Nutrition: Dysphagia: minced/nectar thick liquid. Total dependence with meals. Needs cueing. 3/4 meals not eaten.

- Weight within normal range, lost 10%
- in the last 6 months.

**PLST:** No CPR, all other measures, including transfers to acute care.

# Mr. K's prognosis is:

- a) More than 1 year
- b) 6-12 months
- c) 3-6 months
- d) < 3 months
- e) I don't know
- f) other

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## **Summary of Prognostic Tools in Advanced Dementia**

#### **General Tools**

RAI-MDS CHESS Scale\*

(Hirdes et al. JAGS 2003;51(1):96-100)

 MDS Mortality Risk Index – Revised (MMRI-R)\*

(Prorock et al. BMC Research Notes, 2010. 16:3:200-208)

 Flacker 1 Year Newly Admitted Revised Index\*

(Flacker et al. JAGS 2003; 51:213-221)

 Flacker 1 Year Long Stay Revised Index\*

(Flacker et al. JAGS 2003; 51:213-221)



(https://www.projectbiglife.ca/elderly)

(Tanuseputro et al. JAMDA 2015;16(10):874-83)

### **Dementia Specific Tools**

ADEPT tool\*

(Mitchell et al. JPSM. 2010; 40(5): 639-651)

FAST tool

Functional Assessment Staging Tool(NHPCO)

\* Available at <u>www.eprognosis.com</u>

# **Test Accuracy: c-statistic**

## If the c-stat is:

- < 0.5 very poor model = 0.5 (same as random chance)
- > 0.7 good model
- > 0.8 strong model
- = 1.0 perfect model

## **Summary of Prognostic Tools in Advanced Dementia**

#### **General Tools**

RAI-MDS CHESS Scale\* c-stat: 0.7

(Hirdes et al. JAGS 2003;51(1):96-100)

 MDS Mortality Risk Index – Revised (MMRI-R)\* c-stat: 0.7

(Prorock et al. BMC Research Notes, 2010. 16:3:200-208)

Flacker 1 Year Newly Admitted Revised Index\* c-stat: 0.7

(Flacker et al. JAGS 2003; 51:213-221)

Flacker 1 Year Long Stay Revised Index\* c-stat: 0.7

(Flacker et al. JAGS 2003; 51:213-221)

Big Life Elderly Calculator c-stat: 0.7

(https://www.projectbiglife.ca/elderly)

(Tanuseputro et al. JAMDA 2015;16(10):874-83)

#### **Dementia Specific Tools**

ADEPT tool\* c-stat: 0.7

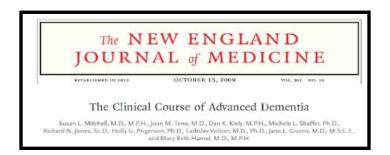
(Mitchell et al. JPSM. 2010; 40(5): 639-651)

### FAST tool c-stat: 0.55

Functional Assessment Staging Tool(NHPCO)

\* Available at <u>www.eprognosis.com</u>

# **Prognosticating in Advanced Dementia**



## Median Survival is 1.3 years

18-month mortality rate = 55%
6 month mortality rate = 25%

# **Prognosticating in Advanced Dementia**

Top 3 Complications	Incidence over 18 months
1. Eating Problem	86%
2. Febrile Episode	53%
3. Pneumonia	41%

## **ADEPT Score** (Advanced DEmentia Prognosis Test)

- 1. Recent LTCH Admission
- 2. Advancing Age
- 3. Male

**Clinical Indicators** 

- 4. Short of Breath
- 5. Pressure Ulcer > Stage 2
- 6. Completely Dependent on ADLs
- 7. Bedbound
  - 8. Insufficient Oral Intake
- 9. Bowel Incontinence
- **10**.BMI < 18.5
- 11.Weight Loss
- 12.CHF

Characteristics         Points in Risk Score         1         0.01           Recent NH admission (within 90 days)         3.3         >2.3         0.05           Age         >3.4         0.06            65-69         1.0         >3.4         0.06           70-74         2.0         >8-9         0.15           75-79         3.0         >9-10         0.17           80-84         4.0         >10-11         0.21           85-89         5.0         >11-12         0.25           90-94         6.0         >13-14         0.34           95-99         7.0         >14-15         0.40           >100         88.0         >15-16         0.46	lity of month 0.06
Score         6-month         12           Characteristics         Points in Risk Score         (minimum score)         0.01           Recent NH admission (within 90 days)         3.3         3.3         3.3         3.3         0.05           Age         3.3         3.3         3.3         3.3         0.05         0.04           Age         1.0         3.3         3.3         0.05         0.06         0.06           70-74         2.0         3.0         3-3-4         0.06         0.06         0.06           75-79         3.0         3.0         3-9-10         0.17         0.10           80-84         4.0         >10-11         0.21         0.25         0.12           90-94         6.0         >11-12         0.25         0.25         0.12           95-99         7.0         >14-15         0.40         0.14-15         0.40           >100         8.0         >15-16         0.46         0.16-17         0.52	
Characteristics         Points in Risk Score         1         0.01           Recent NH admission (within 90 days)         3.3         >2.3         0.05           Age         3.3         >2.3         0.06           65-69         1.0         >3.4         0.06           70-74         2.0         >8-9         0.15           75-79         3.0         >9-10         0.17           80-84         4.0         >10-11         0.21           85-89         5.0         >11-12         0.25           90-94         6.0         >13-14         0.34           95-99         7.0         >14-15         0.40           >100         8.0         >15-16         0.46	
Characteristics         Points in Risk Score         (minimum score)         I           Recent NH admission (within 90 days)         3.3	0.06
Risk Score         >1-2         0.04           Recent NH admission (within 90 days)         3.3         >2-3         0.05           Age	
Recent NH admission (within 90 days)       3.3       >2.3       0.05         Age       >3.4       0.06         65-69       1.0       >6-7       0.10         70-74       2.0       >8-9       0.15         75-79       3.0       >9-10       0.17         80-84       4.0       >10-11       0.21         85-89       5.0       >12-3       0.29         90-94       6.0       >13-14       0.34         95-99       7.0       >14-15       0.40         >100       8.0       >15-16       0.46	0.08
Age         >3-4         0.06           65-69         1.0         >6-7         0.00           70-74         2.0         >8-9         0.12           75-79         3.0         >9-10         0.17           80-84         4.0         >10-11         0.21           85-89         5.0         10         0.25           90-94         6.0         >13-14         0.34           95-99         7.0         8.0         14-15         0.40           >100         8.0         >15-16         0.46         0.46	0.08
Age       See       S	0.11
65-69 $1.0$ $>6-7$ $0.10$ $70-74$ $2.0$ $>7-8$ $0.12$ $75-79$ $3.0$ $>9-10$ $0.17$ $80-84$ $4.0$ $>10-11$ $0.21$ $85-89$ $5.0$ $>11-12$ $0.25$ $90-94$ $6.0$ $>13-14$ $0.34$ $95-99$ $7.0$ $8.0$ $>15-16$ $>100$ $8.0$ $>15-16$ $0.46$	0.15
70-74 $2.0$ $>7-8$ $0.12$ $75-79$ $3.0$ $>8-9$ $0.15$ $80-84$ $4.0$ $>10-11$ $0.21$ $85-89$ $5.0$ $>11-12$ $0.25$ $90-94$ $6.0$ $>12-13$ $0.29$ $95-99$ $7.0$ $>14-15$ $0.40$ $>100$ $8.0$ $>15-16$ $0.46$	0.23
75-79       3.0       >9-10       0.13         80-84       4.0       >10-11       0.21         85-89       5.0       >11-12       0.25         90-94       6.0       >13-14       0.34         95-99       7.0       >14-15       0.40         >100       8.0       <15-16	0.26
80-84       4.0       >10-11       0.21       0.21         85-89       5.0       >11-12       0.25       0.25         90-94       6.0       >12-13       0.29       0.25         95-99       7.0       >13-14       0.34       0.34         >100       8.0       >15-16       0.40       0.40	0.30
85-89       5.0       >11-12       0.25         90-94       6.0       >12-13       0.29         95-99       7.0       >14-15       0.40         >100       8.0       >15-16       0.46	0.33
85-89       5.0       >12-13       0.29         90-94       6.0       >13-14       0.34         95-99       7.0       >14-15       0.40         >100       8.0       >15-16       0.46         >16-17       0.52	0.37
90-94       6.0       >13-14       0.34         95-99       7.0       >14-15       0.40         >100       8.0       >15-16       0.46         >16-17       0.52	0.42
95-99     7.0     >14-15     0.34       >100     8.0     >15-16     0.40       >100     0.52     0.52	0.47
>100 8.0 8.0 <b>&gt;15-16</b> 0.46 <b>&gt;16-17</b> 0.52	0.52
>16-17 0.52	0.57
	0.67
>17-18 0.57	0.71
Male         3.3         >17-18         0.57           >18-19         0.64	0.76
Shortness of breath 2.7 >19-20 0.67	0.79
At least one pressure ulcer > Stage 2 2.2 >20-21 0.73	0.84
ADL score = 28 <sup>a</sup> 2.1 >21-22 0.77	0.87
Bedfast most of day 2.1 >22-23 0.83	0.90
Insufficient oral intake 2.0 >23-24 0.83	0.91
Bowel incontinence <sup>c</sup> 1.9 >24-25 0.88	0/94
BMI < 18.5 kg/m         1.8         >25-26         0.88	0.96
Weight loss <sup>d</sup> 1.6         >27-28         0.95	0.90
Congestive heart failure         1.5         >28-32         1.00	1.00

Mitchel. J Am Med Assoc 2010

Advanced Dementia Prognostic T	ool (ADEPT)	ADEPT Scoring			
Patient Characteristics, Point Scores, and Associated Six-			Observed Probability of		
Month Survival Probabilities		Total Risk	Death		
		Score	6-month	12-month	
Characteristics	Points in	1	0.01	0.06	
	<b>Risk Score</b>	(minimum score)			
Recent NH admission (within 90 days)	3.3	>1-2	0.04	0.08	
Recent Wir dumission (within 50 days)	3.5	>2-3	0.05	0.11	
A = -		>4-5	0.06	0.15	
Age		>6-7	0.10	0.23	
65-69	1.0	>7-8	0.12	0.26	
70-74	2.0	>8-9	0.15	0.30	
75-79	3.0	>9-10	0.17	0.33	
80-84 <b>TOL</b>	4.0	>10-11	0.21	0.37	
75-79 80-84 85-89 90-94 95-99 <b>TOTAL</b> <b>POINTS</b> <b>POINTS</b> <b>21.8</b>	5.0	>11-12	0.25	0.42	
90-94	6.0	>12-13	0.29	0.47	
95-99	7.0	>13-14	0.34	0.52	
	_	>14-15	0.40	0.57	
>100	8.0	>15-16 >16-17	0.46	0.62	
		>16-17	0.52	0.87	
Male	3.3	>17-18	0.64	0.71	
Shortness of breath	2.7	>19-20	0.67	0.79	
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ADL score = 28	2.1	>21-22	0.77	0.87	
Bedfast most of day	21	>22-23	0.83	0.90	
Insufficient oral intake	2.0	>23-24	0.83	0.91	
Bowel incontinence	1.9	>24-25	0.88	0/94	
BMI < 18.5 kg/m	1.8	>25-26	0.88	0.96	
Weight loss	1.6	>26-27	0.88	0.90	
		>27-28	0.95	1.00	
Congestive heart failure	1.5	>28-32	1.00	1.00	

Mitchel. J Am Med Assoc 2010

# So what would you actually say?



Prognostic Tools

**ADEPT**: Risk of 6-month mortality: 77% and 12-month risk of mortality: 87%

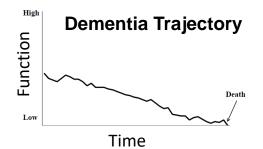
**MMRI-R**: Risk of 6-month mortality is 79%

Flacker Index: Risk of 1-year mortality is 82%

"Out of 100 LTC home residents with similar features, 77 will die and 23 will survive over the next half year.

Risk calculators **cannot** predict the future for any one individual. Risk calculators give an estimate of **how many** people with similar risk factors will live and die, but they cannot identify **who** will live and who will die."

# **Eventualities...**



#### Clinical Course

- Eating problems (85%),
- Infections (50% in the last 3 months; 40% use abx in the last 2 weeks)

#### Transfers from LTCH to Acute Care

- 1.6 in the last 3 months, 30% die in acute care in ON
- Medication Rationalization



# **Cancer Numbers in Canada**

### 1 in 2

#### Canadians will develop cancer in their lifetimes

### 1 in 4

Canadians will die of cancer

### 80,800

The number of Canadians who died of Cancer in 2017

Canadian Cancer Society, 2018

# **Cancer Numbers in Ontario**

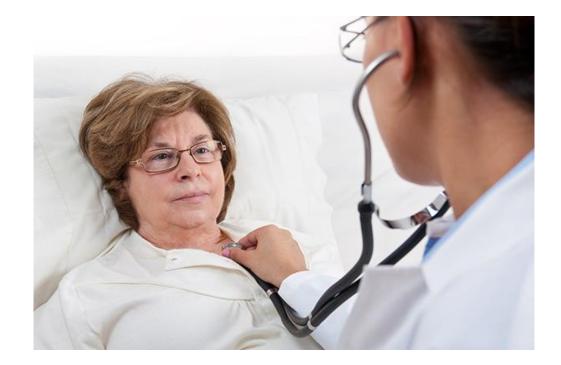
### Lung cancer

Is the leading cause of cancer deaths in men and women in Ontario

### 7,100

#### Ontarians died of lung cancer in 2017

# Meet Ms. B



https://www.medpagetoday.com/resource-centers/advances-in-lung-cancer/estrogen-monotherapy-older-women-lung-cancer/2540

# **Ms. B** 73 y.o. F, Metastatic NSCLC lung to bone, brain, spine, EGFR mutation+

Progressed on afatinib, tagrisso, started on cis/pem, previously received whole brain radiation and XRT to spine for spinal cord compression

Admitted now for worsening leg weakness

**Function:** PPS 50%, ECOG 3, cognitively intact, no dyspnea, +weight loss and anorexia

**SDM:** Sister is default SDM

**PLST:** No CPR, all other measures, including transfers to acute care

### Ms. B: Worsening back pain and bilateral leg weakness

- Admitted to acute care to rule out spinal cord compression
- Ongoing issues with count recovery (anemia/thrombocytopenia)
- Not a candidate for further spine XRT or systemic therapy

#### MRI spine:

 Progression of disease at site where she previously was radiated x 2



# Ms. B's prognosis is:

- a) 1-7 days?
- b) 2-4 weeks?
- c) 2-3 months?
- d) > 3 months?
- e) I don't know
- f) other

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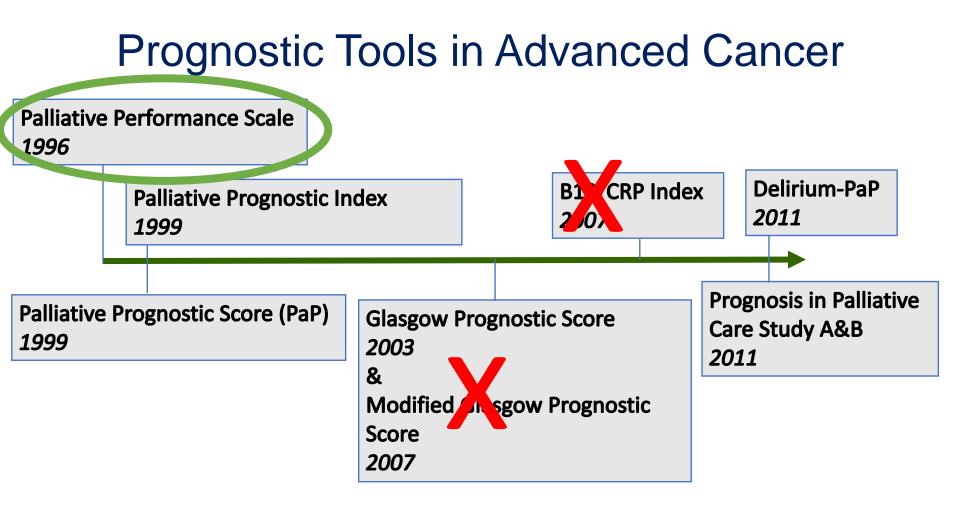
#### **Review Article**

# Prognostic Tools in Patients With Advanced Cancer: A Systematic Review





CrossMark



# Palliative Performance Scale

- Oldest, studied in greatest number of patients
- Studied primarily in inpatient settings and in patients with cancer (but also studied in ambulatory cancer setting)
- Appears to be a good predictor of mortality for patients in palliative care units
- PPS is most accurate in predicting early deaths (<2 weeks)</p>

#### Palliative Performance Scale (PPSv2) version 2

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

# Palliative Performance Scale

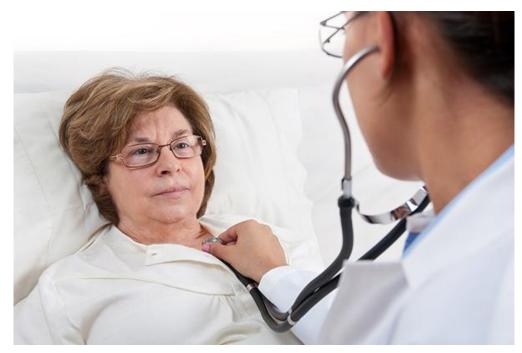
3 distinct bands present for median survival for cancer patients admitted to PCU:

- 10%-20%: Median survival 6 days
- 30%-50%: Median survival 41 days
- 60%-70%: Median survival 108 days

# **Comparing Tools: Performance Status**

<u>c-stats</u> ECOG 0.64 PPS 0.63 KPS 0.63

# Back to Ms. B



### PPS 50%: Median survival 41 days

https://www.medpagetoday.com/resource-centers/advances-in-lung-cancer/estrogen-monotherapy-older-women-lung-cancer/2540

# But her PPS was 50% even before her cancer diagnosis!

# What about rate of decline?

Prognostic tools are only a "snapshot" in time



## Revisiting the Palliative Performance Scale: Change in scores during disease trajectory predicts survival

#### Abstract

**Background:** The Palliative Performance Scale (PPS) on admission is a predictor of survival. However, it is not highly discriminating for mid-range scores. 'PPS Change' between two time points considers the disease trajectory, and may improve the scale's utility.

Aim: The aim of this study is to determine if a change in PPS scores between two significant time points predicts survival.

**Design:** This prospective cohort study examined 'Change on Admission', 'Change at Week I', and 'Change at Week 2'. We followed patients until death or 6 months, whichever was earlier. Cox regressions were used to determine if the Change scores were predictors of survival, adjusting for age, sex, diagnosis category, Charlson Index, and Do-Not-Resuscitate order.

Setting/Participants: The sample consisted of patients referred to the palliative care service.

**Results:** All three Change scores were independent predictors of survival. The greater the change, the poorer the prognosis. At week 1, when compared to 'PPS Change  $\leq 10\%$ ', 'Change 11% –30%' and 'Change > 30%' increased the hazard ratios by 1.70 (95% CI 1.10–2.63) and 3.14 (95% CI 1.77–5.59), respectively. At week 2, when compared to 'PPS Change  $\leq 10\%$ ', 'Change 11% –30%' and 'Change > 30%' increased the hazard ratios by almost 3- and 8-fold, respectively. The same magnitude of Change scores also has higher hazard ratios as patients' hospitalization progressed.

**Conclusions:** The magnitude of change in PPS score during the disease trajectory is associated with one's survival and is a potentially useful prognostication tool. Further research is needed to extend on our work.

# How does PPS fare for frailty?

#### Clinical Frailty Scale\*

I Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

**4** Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.



**7** Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



**9. Terminally III** - Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

#### Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.

 \* I. Canadian Study on Health & Aging, Revised 2008.
 2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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## Enhancing Communication in End-of-Life Care: A Clinical Tool Translating Between the Clinical Frailty Scale and the Palliative Performance Scale

Daphna Grossman, MD,<sup>a,b</sup> Mark Rootenberg, MA(c), HBSc,<sup>a,c</sup> Giulia-Anna Perri, MD,<sup>a,b</sup> Thirumagal Yogaparan, MD,<sup>d,e</sup> Maria DeLeon, RN, BScN,<sup>f,g</sup> Sue Calabrese, RN, MN,<sup>f,g</sup> Cindy J. Grief, MD, MSc,<sup>b,i</sup> Jennifer Moore, MD,<sup>b,j</sup> Ashlinder Gill, PhD(c), HBSc,<sup>j,k</sup> Kalli Stilos, RN, MScN,<sup>l,m</sup> Patricia Daines, RN, MN,<sup>m,l</sup> Camilla Zimmermann, MD, PhD,<sup>n,o</sup> and Paolo Mazzotta, MD, MSc<sup>b,j</sup>

JAGS 62:1562–1567, 2014

## Table 3. Proposed Conversion Chart Outlining Corresponding Clinical Frailty Scale (CFS) and Palliative Performance Scale (PPS) Scores

CFS	PPS
3–4	70–90
5	60
6	40–50
7	10–30



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Home / Archive / Volume 2, Issue 2

#### Research

# Introducing the Palliative Performance Scale to clinicians: the Grampian experience



Gordon Linklater<sup>1</sup>, Sally Lawton<sup>1</sup>, Shona Fielding<sup>2</sup>, Lisa Macaulay<sup>1</sup>, David Carroll<sup>1</sup> and Dong Pang<sup>3</sup>

Author affiliations +

#### Abstract

**Objectives** The Palliative Performance Scale (PPS) was introduced across NHS Grampian. Our aim was to determine how practical and useful the PPS was for clinicians looking after palliative patients in a variety of settings.

Methods A prospective audit approach was used in primary, secondary and nursing home care settings who. Demographic and assessment data were gathered for 3 months; feedback was gathered at the end of the data collection phase. Patient follow-up status was determined at 12 months.

**Results** Fifteen clinical sites participated and feedback was obtained from all clinical areas (n=30). Most respondents found the PPS easy to use and that it helped recognise disease progression in cancer patients, but not in patients with dementia/frailty. Assessment data were gathered on 666 patients. Sixty per cent had a malignant diagnosis and 62.5% of the sample died within 12 months. Lower PPS scores at initial assessment indicated poorer prognosis. Median survival figures differed from previously published data. Falling PPS scores increased the risk of death compared with patients whose PPS scores remained static or improved.

**Conclusion** Clinicians found the PPS to be a quick, useful way of assessing and reviewing functional changes in palliative patients. However, it may not identify the subtle changes in individuals with advanced dementia. The survival figures confirm that caution is needed in generalising survival data across different settings and populations. Further work is needed to examine changing functional status in patients with non-malignant diseases or dementia/frailty. http://www.pips.sgul.ac.uk/pipsforma.php



# THE PiPs PROGNOSTICATOR

Home PIPS A PIPS B

#### This is PIPS-B

The PiPS-B score is as least as good as a multi-professional clinical estimate of survival and is significantly more accurate than a uni-professional estimate (i.e. doctor or nurse). To calculate the PiPS-B score you must complete all of the items on this on-line form.

Please note - this scale should only be used if recent blood result data are available. If recent blood results are not available then you should use <u>PiPS-A</u> (this will provide a prediction which is at least as accurate as a multi-professional survival estimate).

Diagnosis	Score			
Male Genital Organs (No=0, Yes=1)	O ALL fields are required for correct scoring			
Distant mets (No=0, Yes=1)				
Bone mets (No=0, Yes=1)				



Home PIPS A PIPS B

You are a doctor and you predicted that the patient would live for weeks

PIPS-A predicts that the patient will live for weeks

PiPS- A predicts that the probability of surviving 14 days is 90%

PiPS-A predicts that the probability of surviving 56 days is **31%** 

#### Warning:

The PiPS score should only be used as an aid to your clinical judgement rather than as a replacement for your prognostic skills

Remember that although PIPS-A scores are as good as a multi-professional estimate of survival, there remains a significant degree of uncertainty regarding any individual's prognosis.

Have the tools changed or confirmed your prediction for Ms. B?

If your prediction is confirmed, have the tools changed how you communicate the prognosis?

# **Congestive Heart Failure**

# **CHF Numbers in Canada**

#### 50,000

#### The number of new cases diagnosed every year

#### 600,000

### Canadians currently living with CHF

#### **50%**

#### The percentage of Canadians who think heart failure can be cured

Heart and Stroke Foundation, 2016

# Congestive Heart Failure (CHF)

- NYHA classification for disease severity
- "Based on data from SUPPORT, Framingham, IMPROVEMENT, and other studies, 1-year mortality estimates are:
  - Class II (mild symptoms)—5%—10%
  - Class III (moderate symptoms)—10%—15%
  - Class IV (severe symptoms)—30%–40%"
- Average 1 year mortality rate in Canada 33%

# Congestive Heart Failure (CHF)

 Framingham Heart Study (1990–1999): 5-year mortality rate 50% when newly diagnosed

Challenges with prognostication for 6- to 12-month mortality

# Meet Mrs. S



Image from https://www.publicdomainpictures.net/en/viewimage.php?image=189146&picture=grandma



84 year old female. She has returned to your LTC facility following her 4<sup>th</sup> admission to hospital in the last year with a CHF exacerbation.

Comorbidities: Mild COPD, diabetes mellitus Type 2, hypothyroidism, osteoporosis

Her PPS is 40.

Mrs. S. and her daughter would like to speak with you about her expected prognosis considering her frequent admissions to hospital.

# What further information will be helpful to determine prognosis?

# **CHF Prognostic factors**



# Mrs. S

- NYHA Class 3 (marked limitation of activity, comfortable only at rest)
- PPS = 40
- RR = 20/min
- Systolic BP = 105
- **BUN = 34**
- Hgb = 112
- Sodium = 128
- Ejection Fraction 20%
- Dry Weight = 54kg



## Mrs. S's prognosis is:

- a) More than 1 year?
- b) 6-12 months?
- c) 3-6 months?
- d) < 3 months?
- e) I don't know
- f) other

Session PIN: 9641

## **Prognostic Tools**

- Levy et al (2006)
- Provides estimate of mean 1-, 2-, and 5-year survival
- Includes clinical factors, laboratory values, heart disease medications, and device therapies
- C-STAT overall 0.729

www.SeattleHeartFailureModel.org

@ ☆

#### Seattle Heart Failure Model ×

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→ C Secure https://depts.washington.edu/shfm/macosx.php

00			Seattle He	art Failure M	lodel (	Calculator		
Survival Mortality	Baselin 1 Year 81% 19%	e 2 Year 5 Year 66% 31% 34% 69%	Intervention           1 Year         2 Year           93%         86%           7%         14%	r 5 Year 66% 34%	100			
Mean life expectancy	3.9	years	7.8 years		0	i ż	3 4	s Years
Clinical		Medications	Diuretics		IV	Lab Data		Devices
Age:	65		Furosemide:	80		Hgb (g/dL):	14	<ul> <li>None</li> </ul>
Gender: Mal	e ‡	Beta-blocker	Bumetanide:	0		Lymphocyte %:	24	O BiV Pacer
NYHA Class:	A ‡		Torsemide:	0		Uric Acid (mg/dL):	6.5	
Weight (kg):	80	Statin	Metolazone:	0		Total Chol (mg/dL	): 190 🔹	BIV ICD
EF:	30 🗘		HCTZ:	0		Sodium:	137 🛟	Other
Syst BP:	120 🗘	Aldosterone blo	cker Chlorothiazid	e: 0 🔹		LBBB		IABP/Vent/UF
Schemic Schemic					QRS > 150 msec		ec	0  Pressors/Inotrop
								Default Values
Intervention	s			Devices			Note: Some d	
ACE-I	ACE-I 🗌 ARB 🗹 Beta-blocker			None		BiV ICD Biv ICD		
Aldosterone blocker			BiV Pac	er				
© Copyright 2004-2015 Wayne Levy and David Linker						UVAD		

### **Prognostic Tools**

- EFFECT model was derived, tested, and intended to be used in patients hospitalized for CHF
- Validated in 24 Ontario hospitals
- C-STAT 0.8 for 30 day mortality and 0.77 for 1 year mortality
- On-line calculator for this risk model is available at:
- http://www.ccort.ca/Research/CHFRiskModel.aspx

### Back to Mrs. S

EFFECT:

- 30 Day Mortality Rate = 32.7%
- 1 year Mortality Rate = 78.8%

Seattle Heart Failure Model
 1 year survival 82.3%
 5 year survival 37.7%

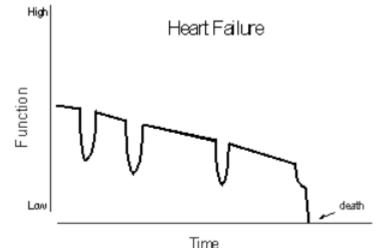
# Drawbacks of using prognostic tools for CHF?

## **Possible Eventualities in CHF**

Average hospital admission days in year of diagnosis: 26.4 days

50% re-admitted within the first year

- Disease trajectory
- Device activation/deactivation
- Sudden death



#### Disease Specific Tools: What do they all have in common?

<b>Cancer:</b> Palliative Prognostic Score	Dementia: ADEPT tool	Congestive Heart Failure: Seattle Heart Failure Model EFFECT tool	<b>COPD:</b> BODE index
<b>Renal:</b> Charlson Comorbidity Index	<b>Liver:</b> MELD Score Child-Pugh Score	<b>Critical Care:</b> APACHE IV	And so on

✓ The accuracy of <u>most</u> of these tools range from 0.6 to 0.8.
 ✓ The use of prognostic tools <u>improves</u> the accuracy of CPS.
 ✓ Clinicians should not exclusively rely on these tools to prognosticate.

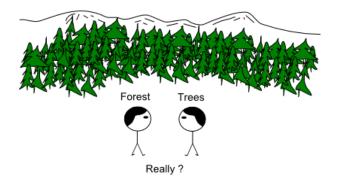


## **Lessons Learned**

- I. We are only accurate about 20% of time, so patients/families get inaccurate information 80% of the time.
- II. Be aware of the common pitfalls (guessing, not personalizing population data, avoidance, being blunt)
- III. Using prognostic tools can improve accuracy and reinforce clinical judgment.
- IV. Prognostication is not a proclamation, rather a process that is revisited, revised and refined.
- V. Best to communicate in probabilistic ranges, percentages and caveats.
- VI. A patient is less likely to die in the setting of preserved functional/performance status. Rate of change is generally important.
- VII. A complication or treatment can change the picture temporarily or permanently.
- VIII. Closer to death, patients may want less information while families may need more.
- IX. Hope is like dignity, and can be crushed in an instant. Be culturally and individually sensitive; not all individuals can or want to hear information about prognosis
- X. Asking 'how long do I have' is partly about prognosis itself but also about need for reassurance in how you will care for them.

#### The Prognosis on Prognostication

## Prognostication is not an event, but a process that is personalized, dynamic, and provisional.





gperri@baycrest.org Irene.Ying@sunnybrook.ca Giovanna.sirianni@sunnybrook.ca





## Please remember to complete your evaluations.

## Evaluations can be found on the Mobile App.

Thank you.

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