

Implementing a Prognostic Indicator in Clinical Practice

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Manchester, UK

*“A Bumpy Ride
on a
Moving Horizon”*

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Agenda

- 3 implementation concepts
- 3 PPS outputs
- 4 stories
- 10 steps to improve prognostication

Parker, Clayton, Hancock, Walder, Butow et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness. JPSM. 2007;34(1)

- ❖ Patients/caregivers had **high levels of information need at all stages** of the disease process regarding the illness, likely future symptoms, life expectancy & information about clinical Rx options.
- ❖ Information needs tended to **diverge** as the illness progressed, with **caregivers needing more & patients wanting less**.
- ❖ Preferred a **trusted health professional** who showed empathy, honesty, encouraged questions & clarified individual information needs & understanding.
- ❖ Most patients/caregivers wanted at least some discussion at the **time of diagnosis** of an advanced, progressive, life-limiting illness, **or shortly after**.
- ❖ However, they wanted to **negotiate** the content & extent of this information.

Implementing Prognostic Tools

- ❖ Implementing in clinical group
- ❖ Implementing in clinical research
- ❖ Implementing in personal practice

1. Implementing in clinical care

- ❖ PPS by all staff [paper, then database]
 - Unit – daily or more often
 - PRT – as above
 - Home Nursing – each visit
- ❖ For inter-professional communication
 - eg. Phone or rounds discussion
 - eg. Unit - patient board
 - eg. PRT cases
- ❖ For prognostic discussion [shortly]

Palliative Performance Scale (PPSv2)

Victoria Hospice Society©

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity No evidence of disease	Full	Normal	Full
90%	Full	Normal activity Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with effort</i>	Full	Normal	Full
70%	Reduced	Unable normal job/work Some disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance	Normal or reduced	Full +/- confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance	Normal or reduced	Full +/- confusion
40%	Mainly in Bed	Unable to do any work Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
30%	Total Bed Bound	Unable to do any work Extensive disease	Total care	Reduced	Full or drowsy +/- confusion
20%	Total Bed Bound	Unable to do any work Extensive disease	Total care	Minimal sips	Full or drowsy +/- confusion
10%	Total Bed Bound	Unable to do any work Extensive disease	Total care	Mouth care only	Drowsy or coma
0%	Dead	X	X	X	X

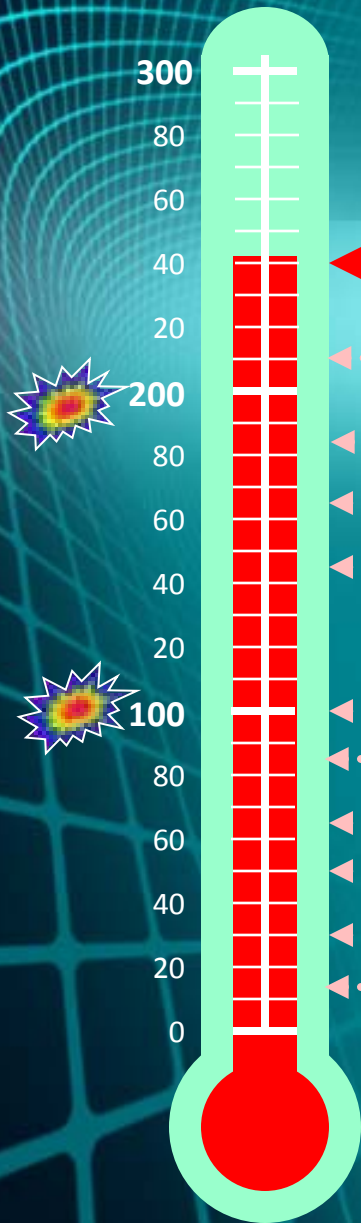
Publications

1. Downing M, Lesperance M, Lau F, Yang J. Sudden functional decline as a sentinel event in EOL palliative patients. *J Pall Med* (under review 2009).
2. Lau F, Maida V, Downing M, Lesperance M, Karlson N, Kuziemy C. Use of the Palliative Performance Scale (PPS) for end-of-life prognostication in a palliative medicine consultation service. *J Pain Symptom Manage*. 2009 Jun;37(6):965-72
3. Lau F, Downing M, Lesperance M, Karlson N, Kuziemy C, Yang J. Using the Palliative Performance Scale to provide meaningful survival estimates. *J Pain Symptom Manage*. 2009; Jul 38(1).
4. Lau F, Bell H, Dean M, Downing M, Lesperance M. Use of the Palliative Performance Scale in survival prediction for terminally ill patients in Western Newfoundland. *J Pall Care* 2008
5. Ho F, Lau F, Downing M, Lesperance M. A validity and reliability study of the Palliative Performance Scale. *BMC Palliative Care*. 2008
6. Maida V, Lau F, Downing M, Yang J. Correlation between Braden Scale and Palliative Performance Scale. *International Wound Journal*. 2008
7. Glare P, Downing M, Lau F, Kirk P. Survey of clinical predictions of survival in far advanced cancer *J Support Care Cancer*; 2008.
8. Glare P, Sinclair C, Downing M, Stone P, Maltoni M, Vigano A. Predicting survival in patients with advanced disease. *European Journal of Cancer* 2008;44(8):1146-56.
9. Lau F, Cloutier-Fisher D, Kuziemy C, Black F, Downing M et al. A systematic review of prognostic tools for estimating survival time in palliative care. *J of Palliative Care*. 2007;23(2)
10. Downing M, Lau F, Lesperance M, Karlson N, Shaw J, Kuziemy C, et al. Meta-analysis of survival prediction With Palliative Performance Scale. *J of Palliative Care*. 2007;23(4):245-54.
11. Lau F, Downing GM, Lesperance M, Shaw J, Kuziemy C. Use of Palliative Performance Scale in end-of-life prognostication. *J Pall Med*. 2006 Oct;9(5):1066-7
12. Anderson, Carsarso, Downing & Lerch. Palliative Performance Scale (PPS): a new tool. *Journal of Palliative Care*. 1996 Spring;12(1):5-11.

2. Implementing in research

- ❖ Surveillance monitoring
 - Canadian Partnership Against Cancer
 - ER visits, etc
- ❖ Timely access to HPEOL care
 - eg. BC MoHS Drug Plan P
 - Bed planning and probable LOS
- ❖ Survival prediction
 - Sentinel drop study
 - Prognostat study

Prognostat reliability study



Week # 17

Prior

Our ongoing thank you and appreciation for the care & attention you demonstrate in supporting this project!!

Current # of Participating Staff = 34

	# Pts	# Dths
Total # (as of Aug 23)	242 (80%)	194

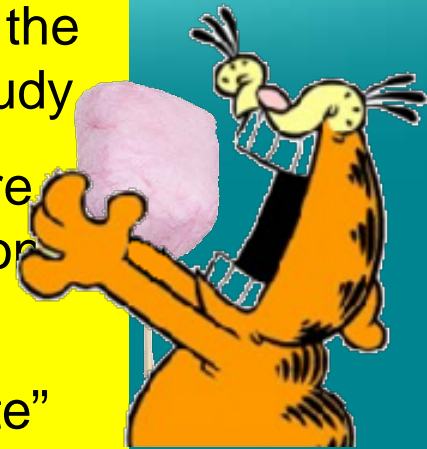
Prognandies Prognola Bars



We have now surpassed 100 of the 300+ patients needed for the study

Thank you to all of you who are participating in the data collection

So don't "procrastinate"
- just 'dig in' and "prognostic-ate"



The PROGNObOX

Prognostat Study

Celebrating **100+** Recruitment

3. Implementing in personal practice

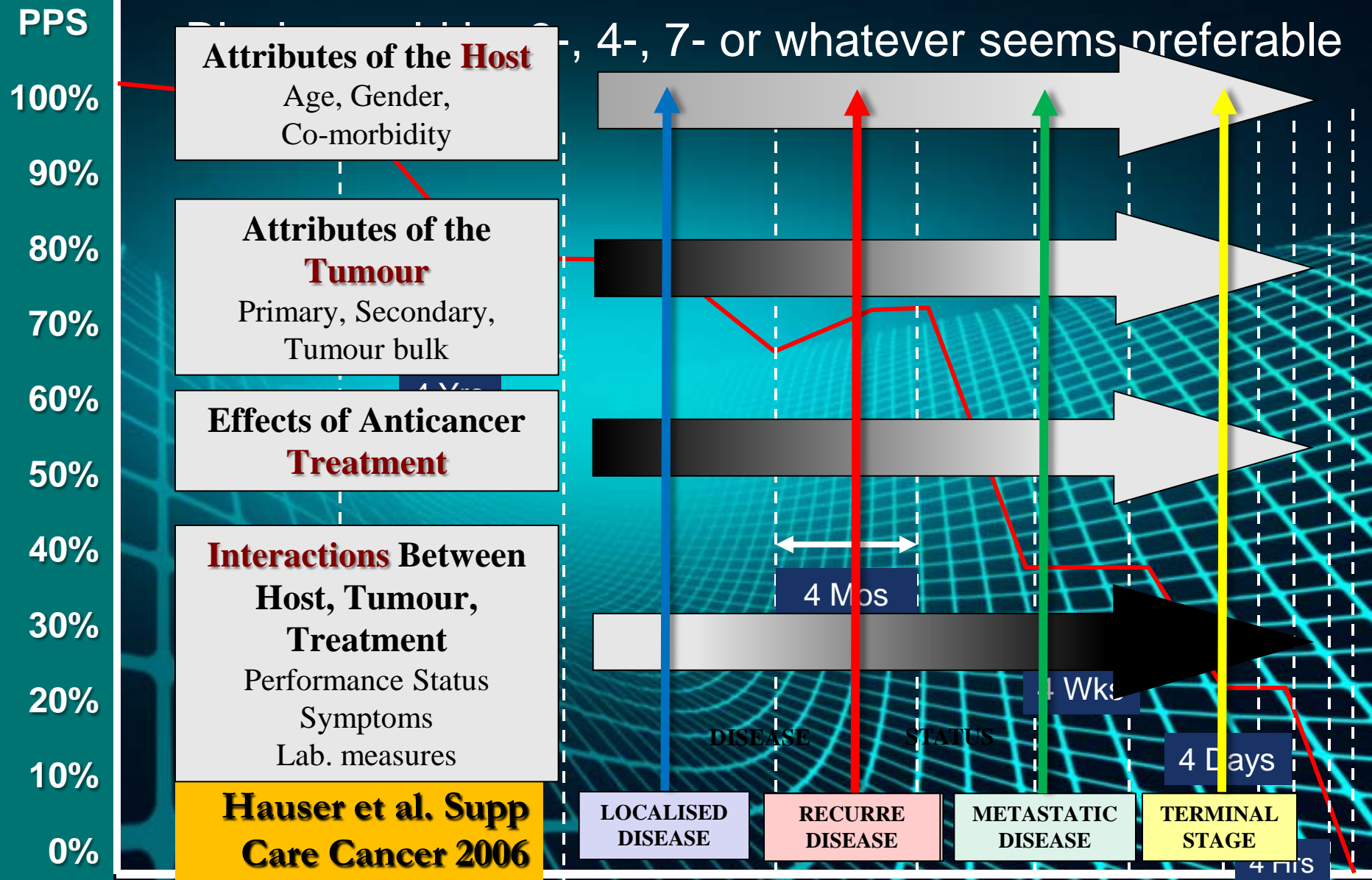
❖ Talking in time-blocks

- This block to prior
- How much change
- How quickly did it change
- If same change next block, then ...

❖ 4 short stories

- 3 pre-death
- 1 family grief

Time Blocks - 'look backward' to 'see forward'

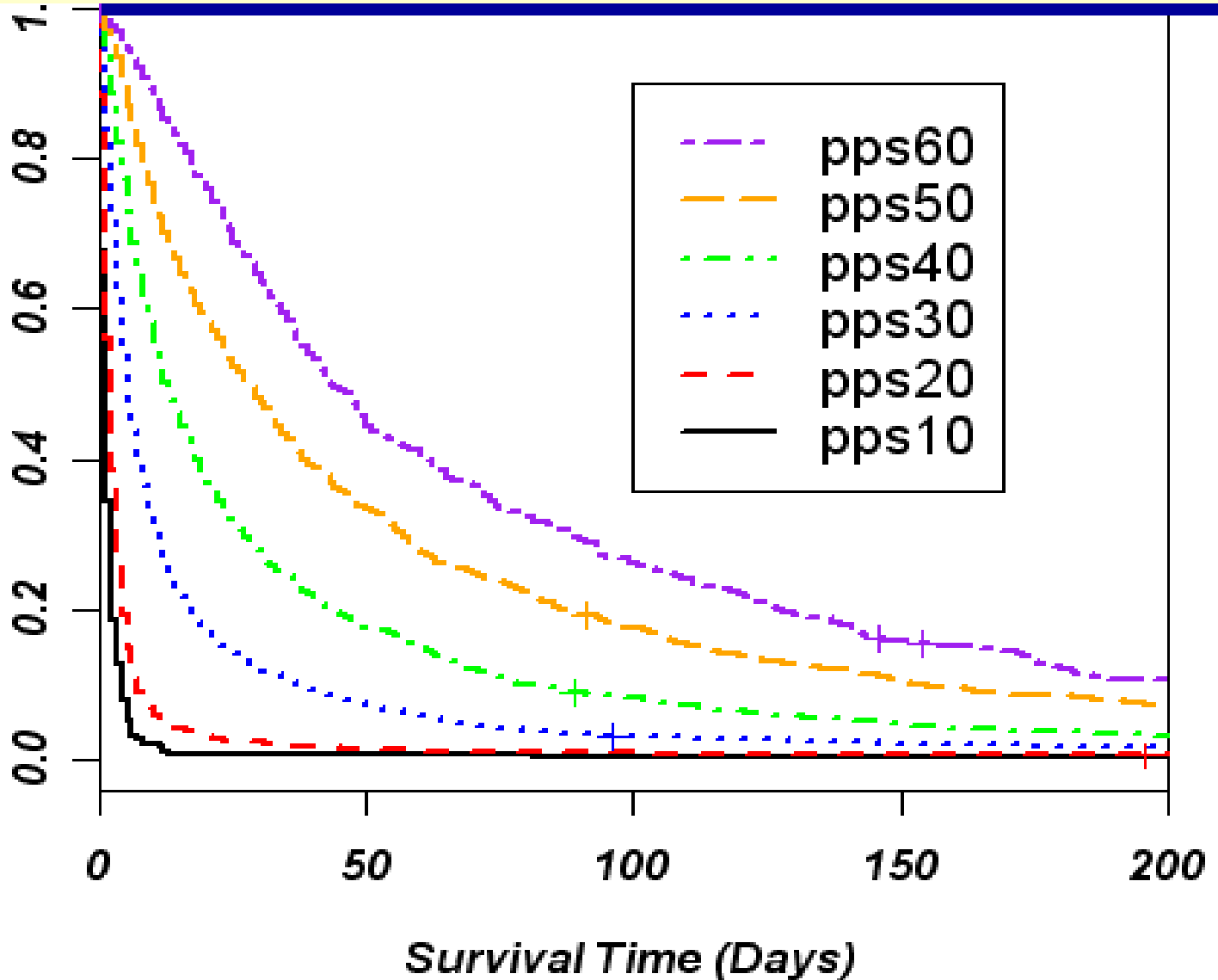


3 METHODS OF USING PPS

1.

VHS Unit & Home (PRT) - 6,066 - 1st PPS

KM-Curves % Survival



2.

PPS Survival Table (%) in days

Lau , Downing et al. J Pain Sympt Management. 2009 July;38(1)

	Survival Rate (%) in Days											Total Cases
	1	3	5	7	14	30	45	60	90	180	365	
PPS 70%	99%	97%	96%	95%	87%	77%	62%	51%	35%	16%	7%	150
PPS 60%	99%	97%	95%	92%	83%	64%	49%	41%	29%	12%	5%	487
PPS 50%	97%	93%	87%	82%	67%	47%	36%	28%	19%	8%	4%	1,055
PPS 40%	94%	82%	73%	66%	46%	27%	19%	15%	9%	4%	1%	1,647
PPS 30%	84%	63%	48%	40%	23%	12%	8%	6%	4%	2%	1%	1,420
PPS 20%	56%	28%	15%	9%	4%	2%	2%	1%	1%	0%	0%	737
PPS 10%	34%	13%	5%	3%	1%	0%	0%	0%	0%	0%	0%	570

Survival Table (%) in days

et al. J Pain Sympt Management. 2009 July;38(1)

“For John, as he has just come into the Unit (at PPS 40%), about ½ of patients like him live > 2 wks, but ½ will also die sooner than that”

“In fact, about 1/3 of patients die in < 7 days”

“There are only a very few (about 1%) who will live 1 year, ... but it is possible for some”

“However, John now has pneumonia, he has become very confused and is quite short of breath ... I think he is on the ‘short side’ of 2 weeks ... and I’m not even sure about this week ... what do you think? ... Let’s talk again tomorrow; we may know more then”

“and only 10% of patients live for 3 months or more”

	Survival Rate (%) in Days											Total Cases
	1	3	7	14	30	45	60	90	180	365		
PPS	00%	07%	95%	81%	81%	7%						150
PPS 50%	97%	93%	87%	82%	67%	47%	36%	28%	19%	11%	4%	1,055
PPS 40%	94%	82%	73%	66%	46%	27%	19%	15%	9%	4%	1%	1,647
PPS 30%	84%	63%	40%	23%	12%	8%	6%	4%	2%	1%	1%	1,420

survival rate of 50%

3.

Story 2

VHS Nomogram

$$0+7+11+14+31=63$$

Points

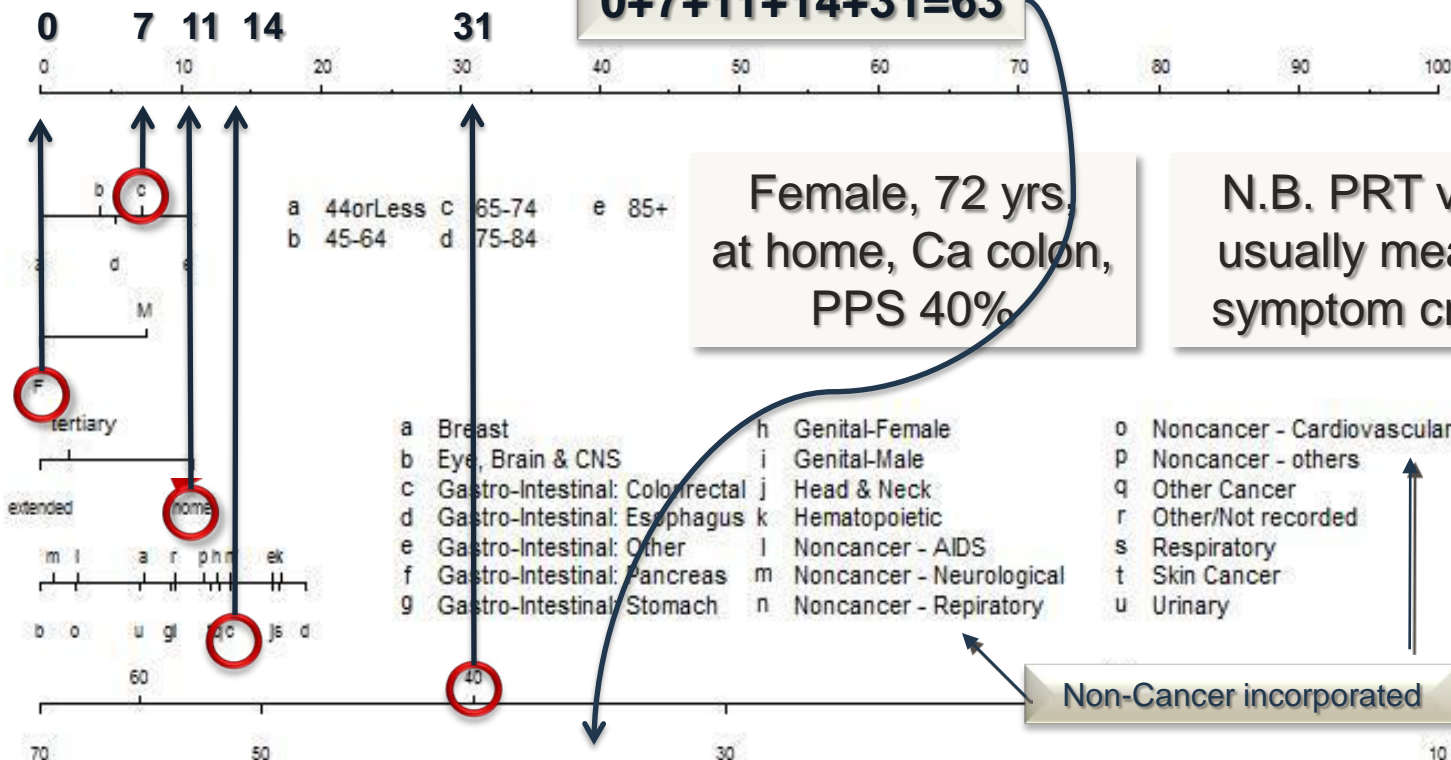
AGE

GENDER

LOCATION

DX

PPS



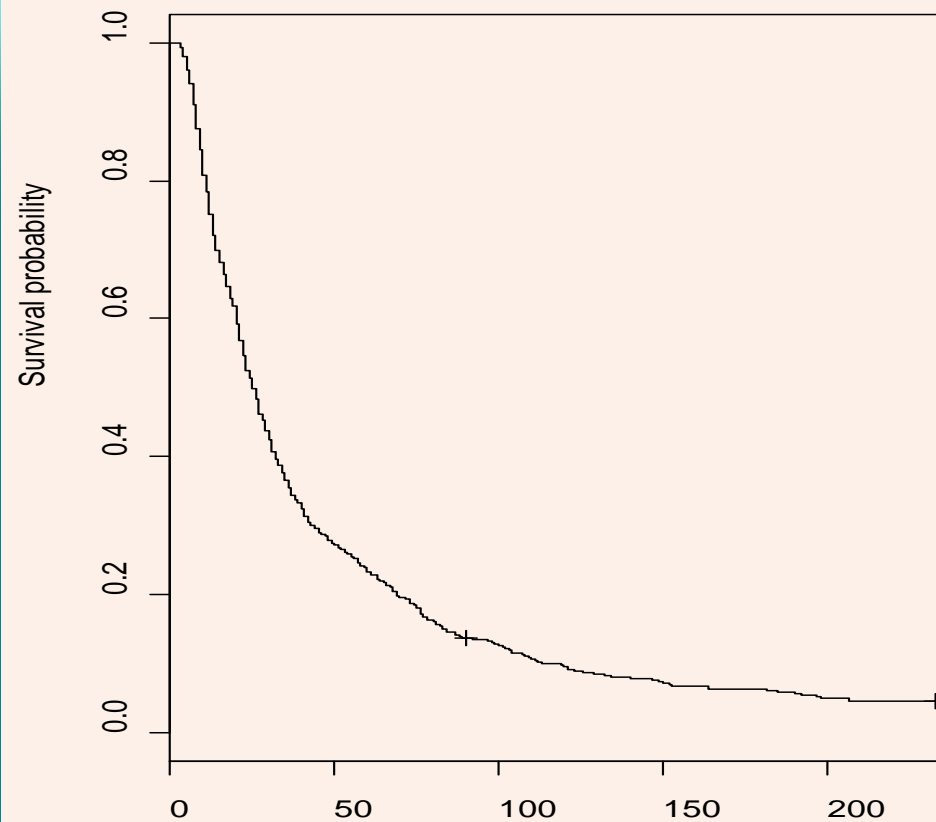
N.B. PRT visit usually means symptom crisis

Female, 72 yrs. at home, Ca colon, PPS 40%

Median survival 10 days

1/2 patients live between 4-30 days

Larger increment drop = shorter survival
[using PPS 40% here as example]



Implementing prognostic tool

- ❖ Printed KM-graphs, Life expectancy table and Nomogram
- ❖ Present to PCP staff dinner meeting
- ❖ Discuss with Nurse leaders
- ❖ Inservice on current research
- ❖ Post the tools in Unit & informal discuss with staff
- ❖ Invitation to research study on Prognostat (collaborators, thermometer, 'celebrations')
- ❖ Using with patients and families

My approach - Pre-death

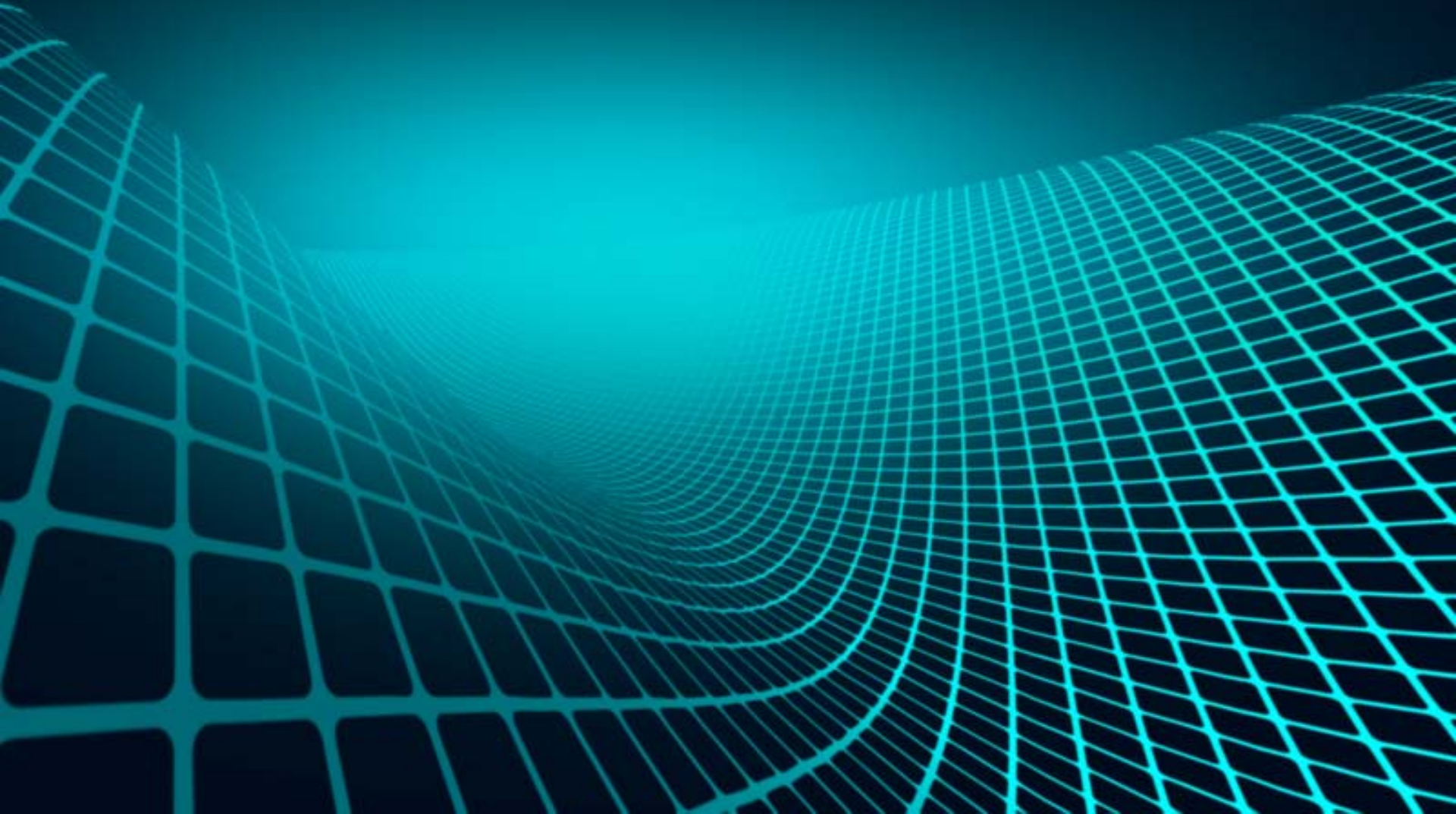
- Fill out nomogram (or PaP, etc) & see if fits with my survival estimate
- Talk in 'blocks', esp. for cancer
 - Perhaps others for non-ca eg. Seattle, CCORT, PIMOA
- Paul's probabilistic approach
- Reassess frequently especially with any new information or triggers
 - Test results – good or bad
 - Improved symptom control & comfort
 - New complication or poor Rx response
- Post-death with family (next slide)

Story 3: Arrival at home; pt died after 12 days at PPS10%; family upset

Story 3

	Survival Rate (%) in Days											Total Cases
	1	3	5	7	14	30	45	60	90	180	365	
PPS 70%	99%	97%	96%	95%	87%	77%	62%	51%	35%	16%	7%	150
PPS 60%	99%	97%	95%	92%	83%	64%	49%	41%	29%	12%	5%	487
PPS 50%	97%	93%	87%	82%	67%	47%	36%	28%	19%	8%	4%	1,055
PPS 40%	94%	82%	73%	66%	46%	27%	19%	15%	9%	4%	1%	1,647
PPS 30%	84%	63%	48%	40%	23%	12%	8%	6%	4%	2%	1%	1,420
PPS 20%	56%	28%	15%	9%	4%	2%	2%	1%	1%	0%	0%	737
PPS 10%	34%	13%	5%	3%	1%	0%	0%	0%	0%	0%	0%	570

Where to from here?



Factors affecting prognosis

- ❖ Disease issues ✓
 - Type, extent, rate, responsiveness, markers ✓
 - Age, gender, racial/ethnic
 - Complications, sentinel events, co-morbidities
- ❖ Symptom issues ✓
 - Functional status, ADL, IADL
 - Symptoms, severity, suffering
- ❖ Goals issues
 - Intent to survive →

Barbot et al. JCO 2008.	
26:15(2538-2542) 2-month survival	
Very curative	73.1%
Moderately curative	45.8%
Palliative non-invasive	30.2%
 - Intent to quality
 - Family issues/drives
- ❖ External issues
 - Environmental/system issues
- ❖ Clinician issues
 - Clinician estimate of survival (CES) ✓
 - Ethics, prudence, judgment

Clinical context also includes these issues

Prognostat tool (current reliability testing)

Category	Items									
Palliative Performance Scale (PPSv2)	100% <input type="checkbox"/>	90% <input type="checkbox"/>	80% <input type="checkbox"/>	70% <input type="checkbox"/>	60% <input type="checkbox"/>	50% <input type="checkbox"/>	40% <input type="checkbox"/>	30% <input type="checkbox"/>	20% <input type="checkbox"/>	10% <input type="checkbox"/>
Illness Trajectory	Stable <input type="checkbox"/>		Unstable <input type="checkbox"/>		Deteriorating <input type="checkbox"/>		Terminal (few days only) <input type="checkbox"/>			
Clinician prediction of survival	≥ 6 months <input type="checkbox"/>	< 6 months <input type="checkbox"/>	< 3 months <input type="checkbox"/>	< 1 month <input type="checkbox"/>	< 1 week <input type="checkbox"/>	< 3 days <input type="checkbox"/>				
Charlson Co-Morbidity Factors	Cerebro-vascular <input type="checkbox"/>	Peripheral vascular <input type="checkbox"/>	Hemiplegia <input type="checkbox"/>	Dementia <input type="checkbox"/>	Diabetes <input type="checkbox"/>	Diabetes + Organ Damage <input type="checkbox"/>	Renal Mod. to Sev. <input type="checkbox"/>	Liver disease Mild <input type="checkbox"/>	Liver disease Mod. to Sev. <input type="checkbox"/>	Peptic ulcer <input type="checkbox"/>
	Any tumour past 5 yrs <input type="checkbox"/>	Metastatic solid tumour <input type="checkbox"/>	Lymphoma <input type="checkbox"/>	Leukemia <input type="checkbox"/>	CHF <input type="checkbox"/>	COPD <input type="checkbox"/>	AIDS <input type="checkbox"/>	Connective tissue <input type="checkbox"/>	Myocardial infarct <input type="checkbox"/>	
Symptoms & Signs	Delirium		No <input type="checkbox"/>	Yes <input type="checkbox"/>	Peripheral Edema		No <input type="checkbox"/>	Yes <input type="checkbox"/>		
	Dyspnea on Exertion		No <input type="checkbox"/>	Yes <input type="checkbox"/>	Skin Pressure Sore		No <input type="checkbox"/>	Yes <input type="checkbox"/>		
	Weight Loss		No <input type="checkbox"/>	Yes <input type="checkbox"/>	Persistent Tiredness		No <input type="checkbox"/>	Yes <input type="checkbox"/>		
	Loss of Appetite		No <input type="checkbox"/>	Yes <input type="checkbox"/>						

Concepts

10 Steps to Improve Prognosis

Story 4 Example

Foresee

Foretell

Ballpark with Exceptions

❖ Caveat:

- *It is impossible to predict for any individual with certainty, but...*

❖ Ballpark:

- *The average person with your illness will live (few weeks to a few months) (3-6 months)...*
- *Treatment, if it works, might extend that time (a month or two)...*

❖ Exceptions:

- *It could be longer, and we will do everything in our power...*
- *Unfortunately, it could also be shorter, so we better get prepared just in case..*

Quill & Epstein, 2009

Framing Effects

Odds of dying versus odds of surviving
50% survival data

The median survival is 6 months

Half of patients with your illness will die in 6 months

Ranges

75% will be alive for 3 months, 25% will live for 9 months

25% will die in the first 3 months, 75% will die in 9 months

- ***Patients will make different decisions depending on whether odds are presented in terms of survival or death***

Understanding both dimensions probably best!!

Tversky; Kahneman. The framing of decisions and the psychology of choice. Science 1981; 211:453-8

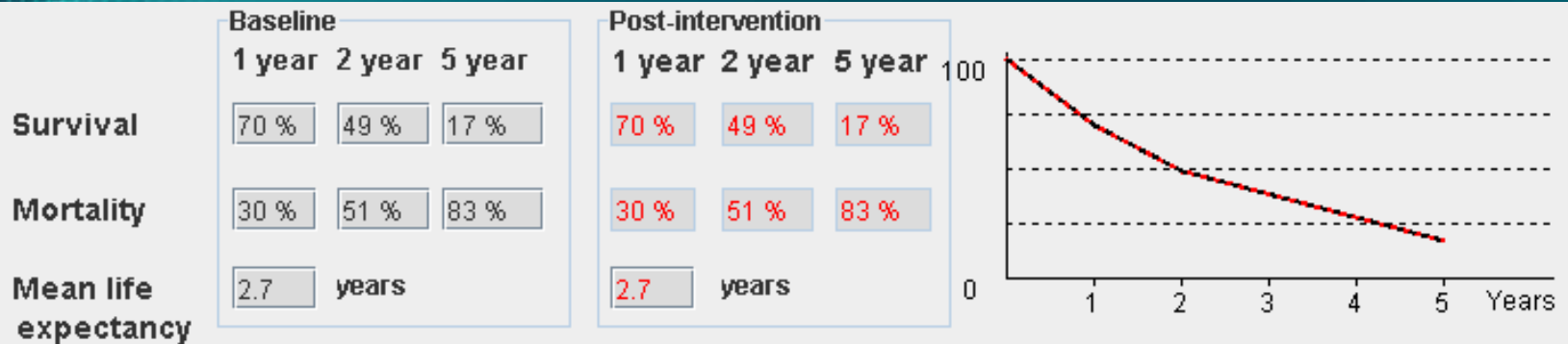
Summary points

- ❖ Prognostics tools can help in clinical care
- ❖ Improvements are occurring
- ❖ Keep it simple (Quill/Epstein)
- ❖ 10 steps to improve prognostication
- ❖ Always a process, not procedure
- ❖ Always changes; reassess over time
- ❖ Foresee & foretell, but not forego

Thank you

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Baseline Characteristics

Clinical

Age

Gender

NYHA Class

Weight (kg)

EF

Syst BP

Ischemic

Medications

ACE-I

Beta-blocker

ARB

Statin

Allopurinol

Aldosterone blocker

Diuretics

Furosemide

Bumetanide

Torsemide

Metolazone

HCTZ

Lab Data

Hgb

Lymphocyte%

Uric Acid

Total Chol

Sodium

QRS >120 msec

Devices

None

BiV Pacer

ICD

BiV ICD

Defaults

Interventions

ACE-I

ARB

Beta-blocker

Statin

Aldosterone Blocker

Devices

None

BiV Pacer

BiV ICD

Note: Some devices may be disabled if CMS clinical criteria are not met. See below.

Canadian Cardiovascular Outcomes Research Team

A Canadian Institutes of Health Research - Heart and Stroke Foundation Interdisciplinary Health Research Team

Read Andre Picard's Globe and Mail interview with Dr. Jack Tu, team leader of CCORT CCORT awarded new CIHR Team of CCORT



EFFECT Heart Failure Mortality Prediction

www.ccort.ca



This prediction score is a method to stratify the risk of death in heart failure patients that can be applied using clinical information available at the bedside. Using the heart failure risk index, one can predict the risk of death at 30 days and one year. The component risk variables are categorized into the following: age, vital signs, laboratory tests, and comorbidities. The risk prediction method is intended to be applied to patients presenting with heart failure in a hospital-based setting, and can be used to stratify risk within hours of hospital presentation. Reference: JAMA 2003;290(19):2581-2587.

The following is a step-by-step guide to use the electronic heart failure risk predictor.

1. Select conventional or SI units of measurement.
2. Enter age in years.
3. Enter respiratory rate at hospital presentation.
4. Select systolic blood pressure at hospital presentation.
5. Enter blood urea nitrogen laboratory value.
6. Select "Yes" if serum sodium concentration <136 mEq/L, and "No" if not.
7. Select "Yes" for the following comorbidities (if present): Cerebrovascular disease, Dementia, Chronic obstructive pulmonary disease, Hepatic cirrhosis, Cancer, and Anemia.
8. Click "Calculate" to calculate the 30-day and one-year scores.
9. Refer to the chart for mortality risk:

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Survival Implications of Sudden Functional Decline as a Sentinel Event using the Palliative Performance Scale (PPSv2)

(Under review)

Abstract

The purpose of this study was to analyse sudden declines in functional status using the Palliative Performance Scale (PPSv2) for patients recently admitted to a palliative care unit to determine if this adversely affects survival. There were 3,328 patients in the cohort over a 13-year period admitted to a tertiary palliative care bed (71.1%) or a residential hospice bed (28.9%). Patient age ranged from 17-102 years old with 51.9% female and 48.1% male; the majority (88.3%) had a cancer diagnosis. Significant findings are summarized as six points: 1) The lower the initial PPS at admission, the higher the likelihood of an abrupt drop; 2) An abrupt decline in function is associated with smaller survival probabilities; 3) Greater increment change in PPS is associated with smaller the survival probabilities; 4) The lower the PPS on admission, the shorter the survival on average; 5) When dropping a specific increment amount, the new survival projection is similar to the PPS level dropped to; and, 6) Sudden or abrupt functional decline is a sentinel event. In summary, this provides evidence to anecdotal clinical experience that an abrupt decline in function often implies shorter survival in the palliative care patient and that it acts as a specific sentinel event in an identified palliative population. Adding this sentinel change in functional status with concurrent illness or complications is anticipated to improve overall accuracy in survival prediction, especially if incorporated into prognostic models, and be of benefit in clinician communication of difficult news.

Variable	PPS drop in first 3 days		Total (% of overall)	P-value
	No Frequency(row%)	Yes Frequency(row%)		
Age			3325	< 0.001
<45	124 (67.8%)	59 (32.2%)	183 (5.5%)	
45-64	481 (60.7%)	312 (39.3%)	793 (23.9%)	
65-74	473 (54.9%)	388 (45.1%)	861 (25.9%)	
75-84	603 (55.6%)	481 (44.4%)	1,084 (32.6%)	
85+	201 (49.8%)	203 (50.3%)	404 (12.2%)	
Gender			3318	0.001
Female	1019 (59.1%)	704 (40.9%)	1,723 (51.9%)	
Male	855 (53.6%)	740 (46.4%)	1,595 (48.1%)	
Location			3328	<0.001
Acute/Tertiary PCU	1281 (54.1%)	1085 (45.9%)	2,366 (71.1%)	
Extended/Residential PCU	601 (62.5%)	361 (37.5%)	962 (28.9%)	
Diagnosis Category			3324	0.03
Breast-Female	200 (59.7%)	135 (40.3%)	335 (10.1%)	
Colorectal	195 (56.7%)	149 (43.3%)	344 (10.4%)	
Lung	382 (54.7%)	317 (45.4%)	699 (21.0%)	
Non-cancer	194 (49.8%)	195 (50.1%)	389 (11.7%)	
Other cancer	783 (58.2%)	563 (41.8%)	1346 (40.5%)	
Prostate	128 (60.7%)	83 (39.3%)	211 (6.4%)	
Initial PPS			3328	< 0.001
PPS 10%	39 (17.7%)	182 (82.4%)	221 (6.6%)	
PPS 20%	62 (18.5%)	273 (81.5%)	335 (10.1%)	
PPS 30%	576 (56.0%)	452 (44.0%)	1028 (30.9%)	
PPS 40%	757 (68.9%)	341 (31.1%)	1098 (33.0%)	
PPS 50%	354 (69.7%)	154 (30.3%)	508 (15.3%)	
PPS 60%	87 (68.0%)	41 (32.0%)	128 (3.9%)	
PPS 70%	7 (70.0%)	3 (30.0%)	10 (0.3%)	

Recognise Limitations of Prognostication

- ❖ Population data versus individual circumstances
- ❖ Treatment response may alter survival prediction, esp. if decline treatment
- ❖ Psychosocial factors of patient and family influence decisions
- ❖ Personal experience in practice and prognostication

❖ Review and Reassess Periodically

What are the triggers(2)

- New diagnosis of serious illness
- Major medical decision with uncertain outcome
- Patient/family ask about prognosis
- Patient family request treatment not consistent with good clinical judgment
- Would you be surprised if the patient died in 6-12 months?
- Patient actively dying