ESMO GOOD SCIENCE BETTER MEDICINE BEST PRACTICE

ESMO PRECEPTORSHIP ON BREAST CANCER

Communicating Bad News to Cancer Patients

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NHMRC Clinical Trials Centre

THE UNIVERSITY OF SYDNEY

Presented by: @BelindaKiely

DISCLOSURES

Advisory boards – Roche

Support for conferences – Roche and Novartis

Speakers fees for educational meetings – Novartis and Roche

BAD NEWS

- **information which adversely & seriously affects an individual's view of their future**

Buckman R. Breaking Bad News: A Guide for Health Care Professionals. 1992:15

BAD NEWS CONVERSATIONS IN BREAST CANCER

- Cancer diagnosis
- Disease recurrence
- Failure of treatment, disease progression
- Irreversible side effects
- Positive results of genetic tests
- Stopping treatment
- Advance care planning
- Hospice and end of life care

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ATTITUDES TO DISCUSSING BAD NEWS

Survey of 500 attendees at a communication skills symposium at ASCO 1998

Question	% responding
In an average month, how often do you have to break bad news to a patient?	
< 5 times	23
5 to 10 times	32
10 to 20 times	31
>20 times	14
Which do you find the most difficult task?	
Discussing diagnosis	4
Telling patient about recurrence	26
Talking about end of active treatment and beginning palliative treatment	45
Discussing end-of-life issues (e.g., do not resuscitate)	20
Involving family/friends of patient	5
What do you feel is the most difficult part of discussing bad news?	
Being honest but not taking away hope	58
Dealing with the patient's emotion (e.g., crying, anger)	25
Spending the right amount of time	10
Involving friends and family of the patient	7

Baile WF. The Oncologist 2000;5:302-311

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Better Communication in Oncology

Increases

- Understanding
- Trust
- Information retention
- Adherence to medication
- Pain management
- Patient centered care
- Survival in metastatic cancer (with PRO's)*

Reduces

- Error
- Complaint / Litigation
- Clinician Burnout
- Consultation time (with question prompt lists)

Kissane, Textbook of Communication in Oncology Ed 2 2016
**Basch E, JAMA, 2017*

HOW ONCOLOGISTS BREAK BAD NEWS

- Systematic review of qualitative studies on the experiences of oncologists breaking bad news
  - 40 articles with data from 600 oncologists across 12 countries
- Identified key themes during the breaking of bad news
- Tendency for oncologists to
  - interpret the absence of questions as unwillingness to know
  - emphasise treatment information more than prognostic information
  - avoid words such as death, cancer, and malignancy
  - provide general time frames for survival and rarely give numbers and percentages
  - explain the inapplicability of statistics to individual subjects

Bousquet et al. JCO 2015 33:2437-2443

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BARRIERS TO BREAKING BAD NEWS

- lack of time
- lack of private rooms
- constant ringing of telephones
- lack of internal communication among health-care professionals
- oncologists' perceptions of insufficient training
- fear of upsetting the patient and their family
- cultural factors – of oncologist and patient
  - lack of interpreter
  - lack of intercultural training
  - patient autonomy vs role of the family – esp when family want to hide information from patient

Bousquet et al. JCO 2015 33:2437-2443

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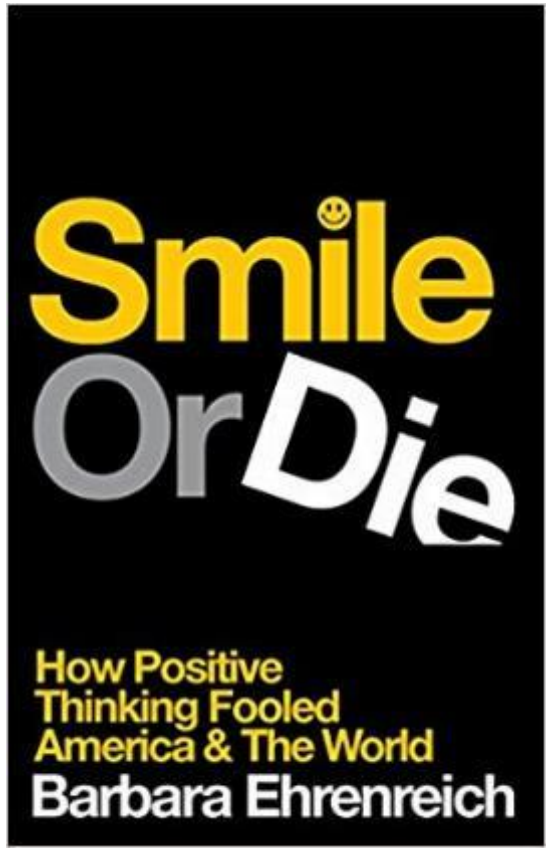
WHAT DO PATIENTS NEED FIRST?

Compassion and Empathic responses

- To know they are not alone
- A caring hand or arm
- Validation of the pain
- Silent presence
- Asking about feelings
- Listening actively
- Practical support
- Empowerment to find their own resources

WHAT PATIENTS DON'T NEED

- Platitudes
- Being told to "think positive."
- Minimising their pain / comparison with others
- Being told to "get over it."
- Avoidance
- Unsolicited advice and information
- Blame



PREPARED

Guidelines for communicating prognosis and end-of-life issues

- **Prepare for the discussion -** Privacy, uninterrupted time, negotiate who should be present
- **Relate to the person**
- **Elicit patient and caregiver preferences -** clarify patient's understanding of situation and amount of detail they want
- **Provide information -** Use clear, jargon-free, understandable language
- **Acknowledge emotions and concerns**
- (Foster) **Realistic hope -** reassure that support, treatments and resources are available, avoid premature reassurance
- **Encourage questions -** Check understanding
- **Document -** in medical record, and in communication to other key health care providers

Clayton JM. MJA 2007, 186 (12) S76-108

ASCO GUIDELINES ON COMMUNICATION

VOLUME 35 · NUMBER 31 · NOVEMBER 1, 2017

JOURNAL OF CLINICAL ONCOLOGY

ASCO SPECIAL ARTICLE

Patient-Clinician Communication: American Society of Clinical Oncology Consensus Guideline

Timothy Gilligan, Nessa Coyle, Richard M. Frankel, Donna L. Berry, Kari Bohlke, Ronald M. Epstein, Esme Finlay, Vicki A. Jackson, Christopher S. Lathan, Charles L. Loprinzi, Lynne H. Nguyen, Carole Seigel, and Walter F. Baile

Systematic review of the literature and a formal multidisciplinary consensus process.

Guidance regarding

- core communication skills
- discussion of goals of care and prognosis
- treatment selection
- end-of-life care
- facilitating family involvement in care
- clinician training in communication skills

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DOCTORS DELIVERING LESS OPTIMISTIC MESSAGES PERCEIVED AS LESS COMPASSIONATE

- 100 patients with advanced cancer watched 2 videos of a doctor discussing prognosis with a patient with advanced cancer who was not fit enough for further treatment
- **Less optimistic message**
  - physician provided explicit information about the lack of further treatment options
- **More optimistic message**
  - physician added a statement considering the possibility of further treatments if the patient improved in functional status
- Better compassion scores given to physicians delivering a more optimistic message
- Physicians delivering the more optimistic message were ranked as more trustworthy

Tanco K, JAMA Oncol. 2015;1(2):176-183

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MAINTAINING HOPE WHEN THE GOAL IS NOT CURE

- Identify other goals to hope for
  - the fewest side effects as possible from the cancer and / or treatment
  - the best quality of life
  - the longest life
- Reassure the patient that you (or a support system /team) will be there for them throughout the illness
  - *"You will not be abandoned."*
- Emphasise what can be done
  - *"There are a lot of other things we can still do to help and support you and make sure you are as comfortable as possible."*

Kadakia, Annals of Oncology 2012. 23 (Supp 3): iii29–iii32; *Clayton JM. MJA 2007, 186 (12) S76-108*

Maintaining hope while communicating bad news

Survey of 126 patients with advanced cancer

Hope Giving Behaviours

- Offered most up-to-date treatment 90%
- Told me my pain will be controlled 87%
- Appeared to know all about my cancer 87%
- Told me all treatment options 83%
- Was occasionally humorous 80%
- Suggested working as a team 78%
- Offered to answer all my questions 78%

Hope Reducing Behaviours

- Appeared nervous or uncomfortable 74%
- Gave my prognosis to family first 58%
- Avoided talking about cancer and only discussed treatment 39%
- Used euphemisms 38%

98% of patients wanted their doctor to:
be realistic, provide an opportunity to ask questions, and acknowledge them as an individual

Hagerty RG, JCO 2005; *23:1278-1288*

FORECASTING

- Right now I am hoping that treatment will go well for you……
- ……in my experience, there usually comes a time when treatment is no longer effective, and I promise I will let you know when that time comes so that we can make the best decisions…”

How long have I got?

My husband is booking us a holiday in Greece next May……

Will I see my son start school?

Should I stop working?

Will I be well enough for my daughter's wedding in February?

WHY DISCUSS PROGNOSIS?

- Helps decision making, planning, end of life care
- Patients who are aware of their life expectancy
  - less likely to undergo aggressive and futile interventions at the end-of-life
  - more likely to engage with palliative care earlier
  - better QOL at end of life and better QOL of carers during bereavement
- Precise understanding not necessary
  - understanding that there was at least a 10% probability of not surviving 6 months enough to change treatment preferences

Weeks et al. JAMA.1998;279:1709-1714 ; Wright AA et al. JAMA 300:1665-73, 2008

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WHEN TO DISCUSS SURVIVAL TIME?

- Ongoing process - often several conversations – values, priorities, preferences,…
- Survey of 206 medical oncologists from Australia and New Zealand

Triggers	% of oncologists reporting always or usually discussing expected survival time
When a patients asks	98
When no further systemic anticancer therapy is planned	91
When estimated expected survival time <6 months	72
Following disease progression on anticancer therapy	61
When estimated expected survival time <1 year	50
At the initial consultation	48
When a patient is hospitalised	44

Vasista A, IMJ in press

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PROGNOSIS-TALK AFTER SCAN-TALK

- 128 audio-recorded encounters b/w oncologists and patients with incurable cancer
  - 36% bad news encounters
- 4 consistent sequential components
  - Symptom-talk, Scan-talk, Treatment-talk, Logistic-talk
- Treatment-talk occupied 50% of bad news encounters
  - 31% of good news encounters
- Only 4 instances of frank prognosis discussion
- Oncologists spend little time discussing scan results and prognostic implications in favour of treatment related talk
- ***Would you like to talk about what this means?***

Singh S. J Oncol Pract. 2017 13(3):e231-e239

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PREFERENCES FOR PROGNOSTIC INFORMATION VARY

- Type and amount of information sought varies
  - Between individuals
  - Within an individual at different time points
- Most want some information
- Many want as much information as possible

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PREFERRED FORMAT FOR EXPLAINING LIFE EXPECTANCY

Survey of 505 people with cancer (median age 58; breast primary 64%)

- 2 formats to explain life expectancy to a hypothetical patient with an estimated survival of 12 months

1. Three scenarios

"If we imagine 100 people in exactly the same situation, then we'd expect:

- ***the 5 to 10 who did best would live 3 years or longer***
- ***the 5 to 10 who did worst would die within 3 months***
- ***the middle 50 would live 6 months to 2 years"***

2. Median survival

"The median survival time in this situation is about 12 months.

This means half of the people will live longer than 12 months and half will die within 12 months."

Kiely. Support care cancer 2013; 21:369–376

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MOST PEOPLE PREFERRED THREE SCENARIOS

- 88% preferred three scenarios
- 5% preferred median survival

Kiely Support care cancer 2013; 21:369–376

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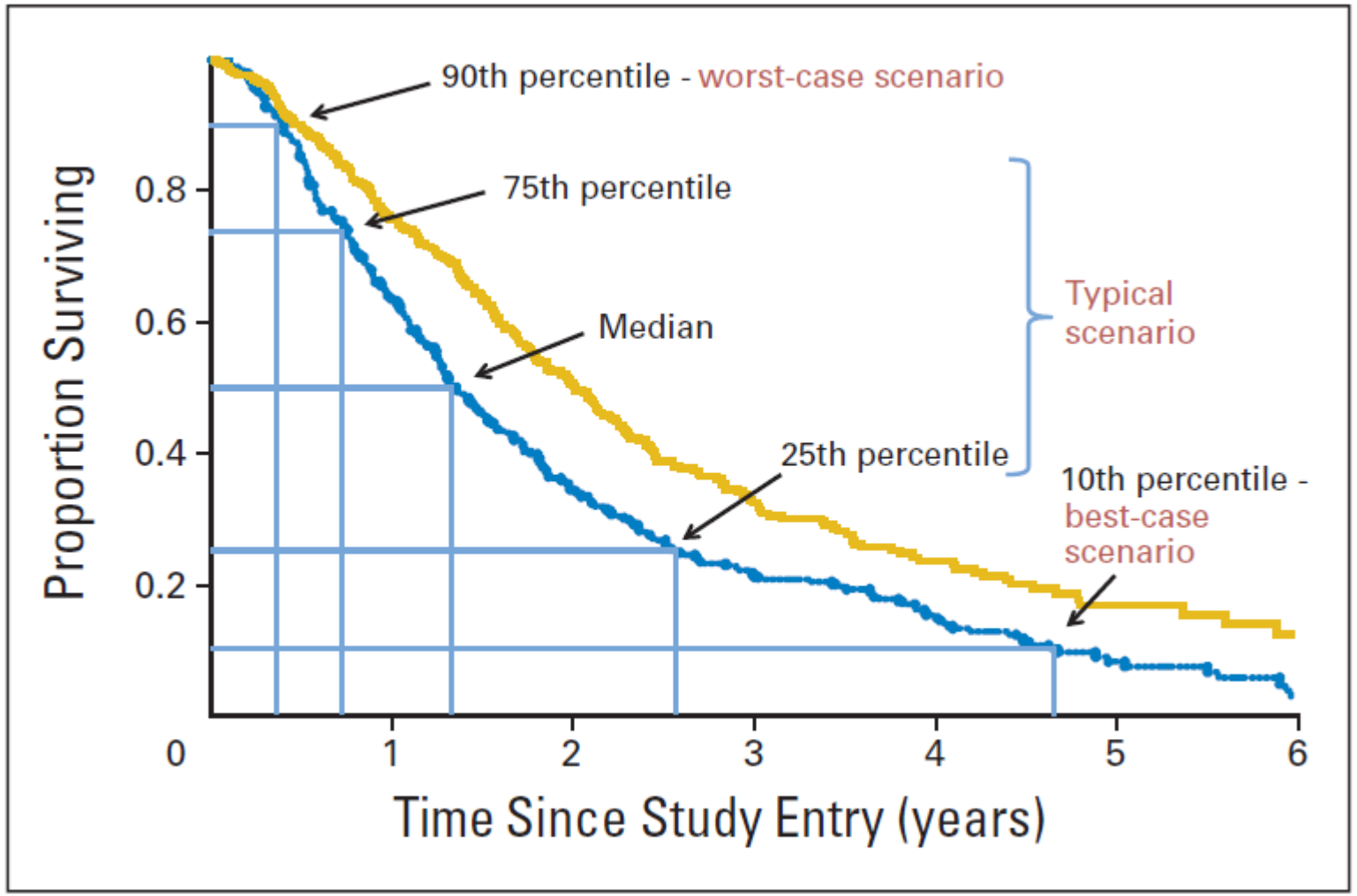
The percentiles of an OS curve provide a useful basis for estimating scenarios for survival



Stockler. BJC 2006; 94, 208 – 212

SIMPLE RULES OF THUMB TO HELP ESTIMATE SCENARIOS FOR SURVIVAL TIME

Worst case ≤ ¼ x median OS

- 5-10 of 100 similar people doing worst

Typical = ½ to 2 x median OS

- Middle 50 of 100 similar people

Best case ≥ 3 x median OS

- 5-10 of 100 similar people doing best

1. Stockler. BJC 2006; 94, 208 – 212; 2. Kiely. JCO 2011; 29(4): 456-463;
3. Kiely. Lung Cancer 2012; 77(3):537-544; 4. West. EJC 2014; 50:1916–1924

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Attitudes of people with advanced cancer to receiving their own expected survival time formatted as 3 scenarios

33 oncologists estimated & explained expected survival to 146 patients with advanced cancer

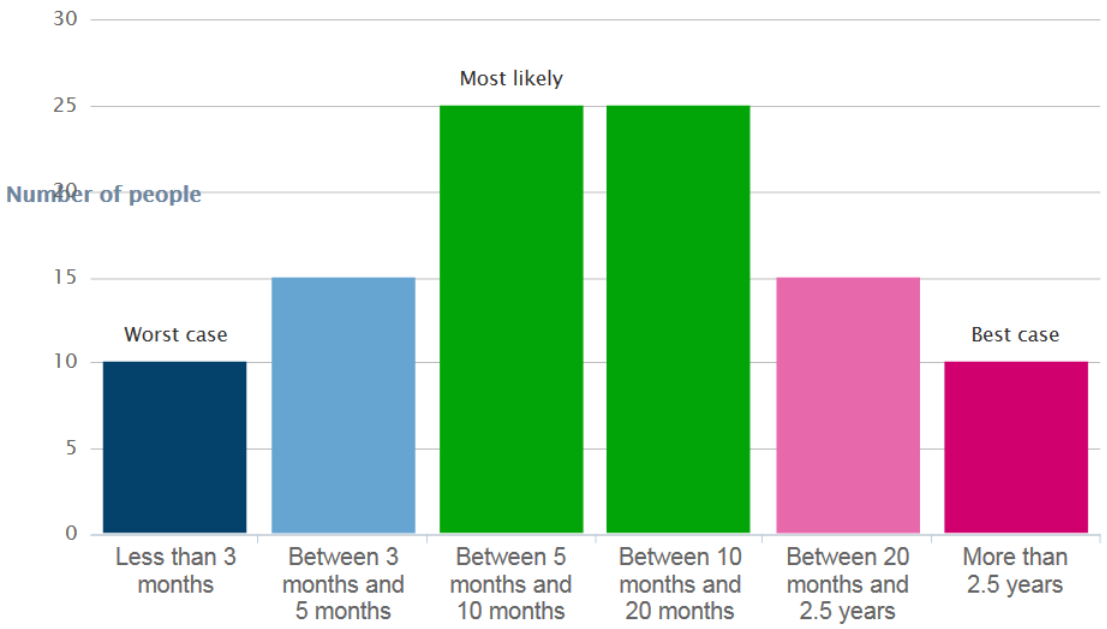
If we imagine 100 people in exactly the same situation, then we'd expect:

- the 5 to 10 who did best would live longer than 6 years
- the 5 to 10 who did worst would die within 6 months
- the middle 50 would live 12 months to 4 years.

This also means that

- half the people would live longer than 2 years and
- half the people would live less than 2 years.

Cancer is very unpredictable. Sometimes that unpredictability acts in your favour



Print for patient and relatives, copy sent to GP and referring doctors

Attitudes of people with advanced cancer to receiving their own expected survival time formatted as 3 scenarios

	(%)* n=146
Having survival time explained this way:	
was helpful	91
helped me make plans	88
improved my understanding	88
was reassuring	64
gave hope	56
was upsetting	41
Receiving a printed summary was helpful	91

* agree and strongly agree (vs. unsure, disagree, strongly disagree)

Kiely BE, Annals of oncology, 2014: 25(suppl 4):iv484.

PATIENT ATTITUDES TO 3 SCENARIOS

Hearing each scenario was helpful*	%
Best-case scenario	92
Worst-case scenario	81
Most likely scenario	86
Preference for scenario to be presented first	
Not important	36
Most likely	34
Best-case	20
Worst-case	10
How scenarios compared with expectations	
Same as expected	46
Better than expected	31
Worse than expected	23

Majority wanted to know the worst-case scenario

77% found information same or better than expected

* agree and strongly agree (vs. unsure, disagree, strongly disagree)

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Kiely BE, Annals of oncology, 2014: 25(suppl 4):iv484.

WHAT IF I GET IT WRONG?

- Avoid providing a single point estimate
- Providing ranges for scenarios
  - more accurate
  - conveys inherent uncertainty of survival estimates

ACCURACY OF ONCOLOGISTS' ESTIMATES OF EXPECTED SURVIVAL

- 5 studies
- Oncologists estimate survival for their patients with advanced cancer

  "Estimate the median survival of a group of similar patients"
- Patients followed for survival

1. Stockler BJC 2006; 2. Kiely JCO 2013; 3. Smith-Uffen SCC 2019; 4. Kiely WCLC abstract 2013; 5. Vasista The Oncologist 2019

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Accuracy of oncologists' estimates of expected survival

<30% of point estimates accurate (within 0.67–1.33 x observed survival)

Simple multiples of oncologists' estimates were accurate for estimating scenarios

Scenario	Expected	Mixed advanced cancers[1] n=102	Mixed advanced cancers[2] n=114	Mixed advanced cancers[3] n=163	Advanced NSCLC[4] n=363	Advanced gastric cancer[5] n=152
				%		
Worst-case ≤ ¼ x doctor's estimate	5-10	4	6	8	10	9
Typical ½ - 2 x doctor's estimate	50	61	63	64	52	57
Best-case ≥ 3 x doctor's estimate	5-10	6	14	5	13	12

1. Stockler BJC 2006; 2. Kiely JCO 2013; 3. Smith-Uffen SCC 2019; 4. Kiely WCLC abstract 2013; 5. Vasista The Oncologist 2019

What numbers do I use to estimate survival?

- Median OS from a clinical trial is a good starting point

Clinical setting	Median OS (months)
ER+ MBC	
1st line aromatase inhibitor[1,2]	34
1st line aromatase inhibitor + CDK4/6 inhibitor[2]	?
1st line chemotherapy[3]	22
HER2+ MBC	
1st line trastuzumab + chemotherapy[4]	33
1st line trastuzumab + pertuzumab + chemotherapy[5]	56
Triple negative MBC	
1st line chemotherapy[6]	12

1. Mouridsen H, JCO 2003; 21:2101-2109; 2. Hortobagyi GN, Annals of Oncology 2018; 29: 1541–1547; 3. Kiely BE, JCO 2011; 29(4): 456-463; 4. Vasista A. The Breast 2017; 31:99-104; 5. Swain SM, NEJM 2015; 372: 724–34; 6. Tutt A, Nat Med 2018; 24:628-37.

EXAMPLES OF USING SIMPLE MULTIPLES TO CONVERT ESTIMATE INTO 3 SCENARIOS

- Fit patient with ER+ MBC starting letrozole
  - Median OS from clinical trials 34 months
    - Typical scenario 18 months to 5 years (1/2 to 2 x 34)
    - Worst-case scenario < 8 months (1/4 x 34)
    - Best-case scenario > 8 years (3 x 34)
- Fit patient with HER2+ MBC starting trastuzumab and pertuzumab
  - Median OS from clinical trials 56 months
    - Typical scenario 2 to 9 years (1/2 to 2 x 56)
    - Worst case scenario < 1 year (1/4 x 56)
    - Best-case scenario > 14 years (3 x 56)

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LIMITATION OF CLINICAL TRIAL ESTIMATES

- Not all “routine practice” patients meet clinical trial eligibility criteria
  - Trial estimates may need to be adjusted down
- Many trials have insufficient follow-up to determine survival times beyond the median, esp. best-case scenario
- May not be a relevant clinical trial
  - Stopping chemotherapy
  - Later line treatments

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SURVIVAL DATA FROM "NON-TRIAL" POPULATIONS PROVIDE USEFUL "REAL WORLD" PROGNOSTIC INFORMATION

- Herceptin program 2001 – 2015[1, 2]
  - whole of population cohort
  - 5899 Australian women with HER2+ MBC receiving trastuzumab
  - median f/up 6.7 years (80 months)
  - Median age 56, 11% >75 yrs
  - 78% started trastuzumab with taxane

1. Daniels B, BMJ Open 2017;7:e014439. doi: 10.1136/bmjopen-2016-014439;

2. Daniels B, The Breast 2018; 38; 7-13

Comparing scenarios for survival for patients with HER2+ MBC starting 1st-line trastuzumab: "real world" v clinical trials

	Median OS	months		
		Worst-case scenario	Typical scenario	Best-case scenario
Herceptin Program[1,2]	**30**	**5**	**13 - 69**	**175***
Clinical trials[3]	33	9	18 - 51	NE

*11th percentile

Worst-case and lower typical scenarios shorter in "non-trial" cohort

Multiples of median still reasonable for estimating scenarios

11% lived longer than 14 years

1. Daniels B, BMJ Open 2017;7:e014439. doi: 10.1136/bmjopen-2016-014439;
2. Daniels B, The Breast 2018; 38; 7-13; *3. Vasista, A. The Breast 2017; 31:99-104*

Oncologists preferred format for explaining expected survival time

Survey of 206 medical oncologists from Australia and New Zealand

Format	% of oncologists reporting to prefer this format
Best-case, typical-case, worst-case scenarios	52
A range of time without numbers, e.g. ‘weeks to months’	22
A range of time with number e.g. ‘6 to 12 months’	17
A unit of time without numbers, e.g. ‘months’	5

Vasista A, IMJ in press

EXAMPLE FROM CLINIC LAST WEEK

- **Fiona**, 42yo beauty therapist, married, 3 children, fit, no comorbidities
- June 2014: Stage 3 breast cancer, lobular, ER+, PR+, HER2-negative
  - Adjuvant AC-Paclitaxel
  - goserelin + exemestane since Nov 2014
- July 2019: presented to GP with acute severe back pain
  - Multiple bone and lymph node metastases, T8 pathological fracture
- ***Can it be cured?***
- ***How long have I got?***

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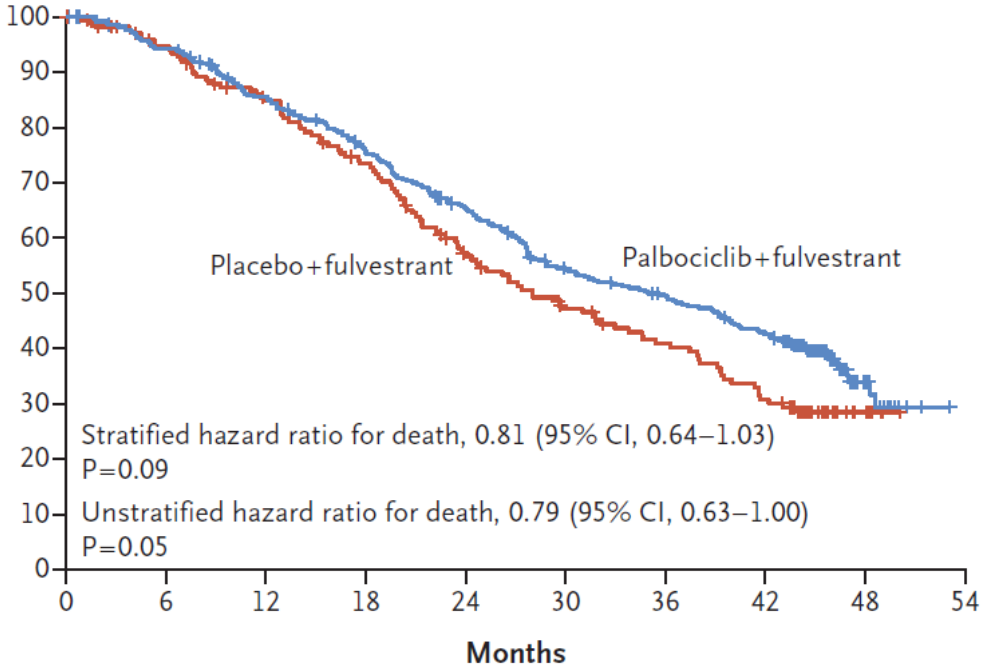
FIONA

- 42yo, ECOG PS 0, ER+, MBC, bone dominant disease
  - relapsed on adjuvant endocrine therapy (OFS + AI) after 5 years
- Wants to pay for fulvestrant + palbociclib
- Paloma 3 trial[1,2]
  - Pre and post-menopausal
  - ER+, HER2-, MBC
  - Relapsed/progressed during endocrine therapy
  - palbociclib + fulvestrant v placebo + fulvestrant
  - **Median OS 35 months** v 28 months



1. NEJM 2015;373:209-19; 2. NEJM 2018;379:1926-36.

Estimating survival for Fiona

- Start with estimate from clinical trial – median OS 35 months
- Estimate 3 scenarios using simple multiples
  - Worst-case < 9 months (<1/4 x 35)
  - Typical 18 months to 6 years (1/2 to 2 x 35)
  - Best-case > 9 years (>3 x 35)

"If we imagine 100 people in exactly the same situation, then we'd expect:

- the 5 to 10 who did best would live longer than 9 years

- the 5 to 10 who did worst would die within 9 months

- the middle 50 would live 18 months to 6 years"

DOCUMENTATION OF PROGNOSTIC DISCUSSIONS

- Survival estimates are rarely documented in medical record/ letters to GP
  - 1344 letters pertaining to 272 pts with advanced cancer (median survival 13 months)
    - word ‘incurable’ included for 93 patients (34%)
    - only 31 patients (11%) had a quantitative estimate of survival time

- Documentation of conversations about prognosis and estimated survival
  - ensures all clinicians involved are aware of what the patient has been told
  - helps patients receive consistent information and care in line with their goals and values

1. *Moth et al. Internal Medicine Journal* 2015; 45(9):909-915

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TAKE HOME MESSAGES

- Breaking bad news must be done with gentleness, kindness and a sense of hope- that all is not lost, and that much can and will be done
- Acknowledge patients as individuals with unique information needs
- Initiate conversations about prognosis, especially if expected survival time is 1 year or less
- Survival times from clinical trials provide a good stating point for survival estimates
- For patients wanting quantitative prognostic information use simple multiples to provide ranges for worst-case, typical and best-case scenarios
- Conversations about prognosis should be documented and accessible

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