THE DO'S AND DON'TS

OF COMMUNICATION ON ADVANCED/ METASTATIC BREAST CANCER

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Metastatic Breast Cancer MBCalliance

ABC GlobAlliance

How to Communicate Disease Progression and Prognosis

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- Dr. Belinda Kiely is a medical oncologist who specializes in breast cancer. She is a Staff Specialist at Concord and Campbelltown hospitals in Sydney, Australia and a Senior Clinical Research Fellow and Oncology Prognostication Program Lead at the NHMRC Clinical Trials Centre, University of Sydney.
- Her research interests include breast cancer treatment, prognostication and survivorship. Dr. Kiely led the development and evaluation of a web-based tool to help oncologists estimate and explain scenarios for survival time to patients with advanced cancer and contributed to the development of CancerSurvivalRates.com, a website helping patients with cancer and their doctors find prognostic information.

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What to expect when living with advanced breast cancer

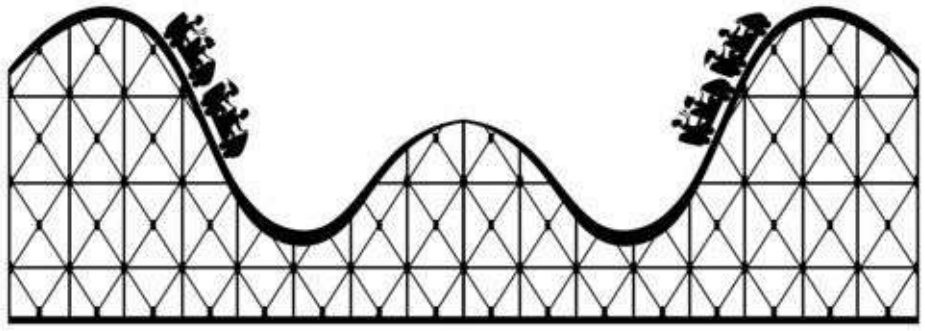
- Many people live many years
- Nearly aways on treatment
- But treatment won’t work forever
- Scans every few months
- Stepping from one treatment to the next
- For most people cure is not possible

Ups and downs like a roller coaster

Disease trajectory is individualized

- varies with subtype of breast cancer, extent of disease, treatment response,…

- Helpful to prepare patients for the likely ups and downs as they move through different treatments
  - Periods of feeling well while treatment is working
  - Periods where cancer progresses and symptoms increase



“Unexpected” deterioration

- Many have a prolonged response to first-line therapy
  - first progression can be a shock
    - often a long time from initial conversations about diagnosis, prognosis
  - patients and doctors can “forget” the cancer is incurable
    - false sense of security
- How should we remind people that treatment will not work forever, the cancer cannot be cured, …

Forecasting

- “Right now I am hoping that treatment will go well for you……

…. there usually comes a time when

treatment is no longer effective,

and I will let you know when that time comes …”

Annals of Oncology 2014, 25 (Supplement 3): iii138–iii142

Importance of prognostic information

- Prognostic information helps people with advanced cancer plan for the future and make informed decisions
- Communicating about prognosis is a fundamental skill for oncologists but there is limited guidance
- Prognostication is daunting
- Patients may receive little or no prognostic information

Barriers to discussing prognosis with patients

- Survey of 206 medical oncologists from Australia and New Zealand
  - family members requesting that prognostic information not be discussed (56%)
  - not knowing expected survival time (46%)
  - time limitations in the clinic (35%)
  - fear of causing stress to the patient and their family (35%)
  - fear of getting the survival estimate wrong (23%)

Vasista A, Intern Med J. 2020 Jan 6. doi: 10.1111/imj.14739.

When and how to discuss prognosis?

- Start conversations early
- Don’t wait for the patient to ask
  - Would you like me to talk about what the future might look like?
  - Is there **something** else you want to discuss?
- Ongoing process - often several conversations
  - values, priorities, preferences, wishes…
  - palliative care services
  - end-of-life care
  - understanding how a person ranks longevity, comfort and independence

Systematic Review: Timing of prognostic discussions

58 studies, guidelines and expert recommendations

Timepoint	Guidelines/ expert recommendations	Studies of doctors	Studies of people with advanced cancer
At first consultation	√	√	√
Prior to commencing treatment	√		
When a patient directly asks	√	√	√
At important transitions (disease progression, stopping treatment, hospitalisation, …)	√		√
When patient expectations don't align with expected prognosis	√	√	√
When no further anti-cancer treatments	√	√	√
When recommending palliative care	√	√	√
When a patient's life expectancy < 12 months	√	√	

Nahm S, et al. Support Care Cancer. 2024.

Scans to evaluate treatment response

- Important to explain
  - the reason for the scan
  - possible results
  - the plan for good news and for bad news
- Acknowledge scanxiety
  - common, transient, peaks before scan and waiting for results[1]
- Discuss delivery of results
  - avoid delays
  - face to face preferable
  - challenge when patients access own scan results online

Bui et al, unpublished work

When the scan shows disease progression

- Be prepared – check result before speaking to patient
- Give the result straight away
  - *“I have the results of the CT scans you had done yesterday and I wanted to go over the results with you if that’s ok.”*
- Express solidarity (eg, *“I wish I had better news.”)*
- Give the bad news clearly and succinctly in plain, nontechnical language
  - “Unfortunately, your cancer has spread to your liver.”
- Pause for the patient to absorb what has been said
- Avoid trying to minimise the bad news or changing the subject
- Reassure that you will help them figure out the next steps

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

When the scan shows disease progression

- Tendency for oncologists to focus on discussing the next treatment
  - Treatment-talk occupied 50% of bad news scan result encounters in one study[1]
  - Only 4 instances of frank prognosis discussion in 33 encounters (3 patient initiated)
- Opportunity to
  - discuss prognostic implications of scan results
  - reassess a patient's goals, priorities, and desire for information
- ***Would you like to talk about what this means?***

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

Forecasting

- Introducing Advanced care planning

  “Your cancer has progressed, but we still have a treatment option.

  Have you considered what you want if this treatment does not work?

  If there is an emergency situation, have you thought about what you want to be done?”

1. J Gen Intern Med 22(10):1429–33

Preferences for prognostic information vary

Type and amount of information sought varies

- between individuals
- within an individual at different times

Some just want the big picture

- is this cancer curable?
- will this cancer shorten my life?

Others want all the details

- numbers and percentages
- best-case scenario and worst-case scenario

Some people don't want to discuss prognosis at all

- Understanding why may help finding a way to discuss it
- Best not to confront a patient with information they do not want unless a compelling reason to
- Decision making does not always require patient to understand detailed prognostic information

Preferred format for receiving information about life expectancy

Survey of 505 Australians with cancer (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:

- *5 to 10 would live 3 years or longer*
- *5 to 10 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."

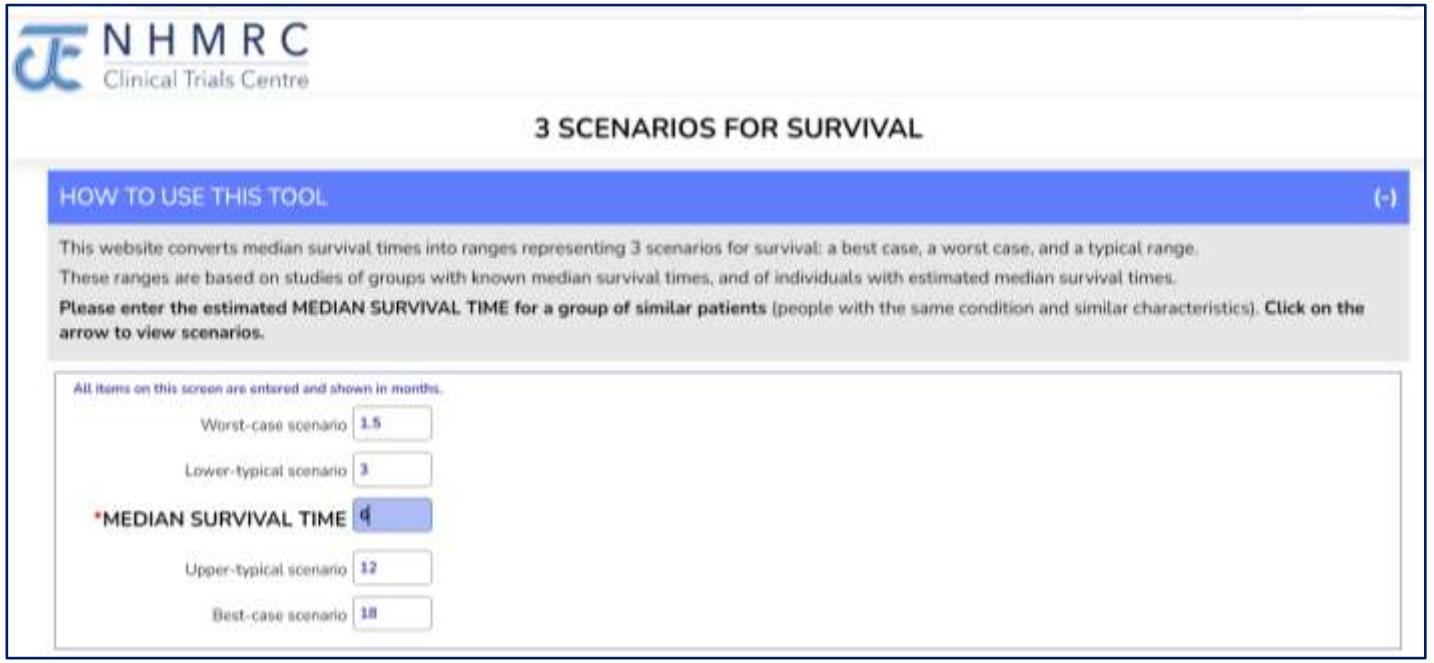
88% preferred three scenarios

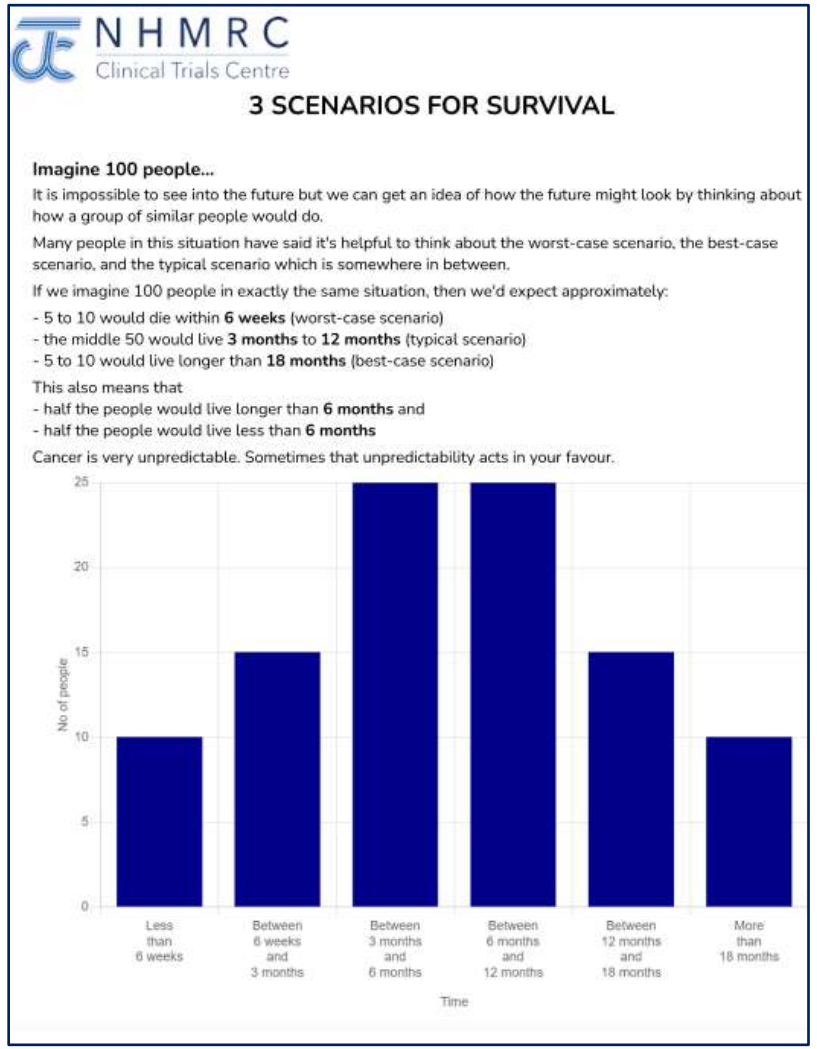
5% preferred median survival

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

https://www.ctc.usyd.edu.au/3scenarios/

- Website to help doctors estimate and explain 3 scenarios for survival
- Input: estimate of “median survival in a group of similar patients”





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

33 oncologists estimated & explained expected survival to 222 patients with advanced cancer

	(%)* n=146
Having survival time explained this way:	
was helpful	91
makes sense	96
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)

Nahm, et al. Supportive Care in Cancer 2022

Patient attitudes to 3 scenarios

Hearing each scenario was helpful*	%
Best-case scenario	92
Worst-case scenario	81
Most likely scenario	86
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

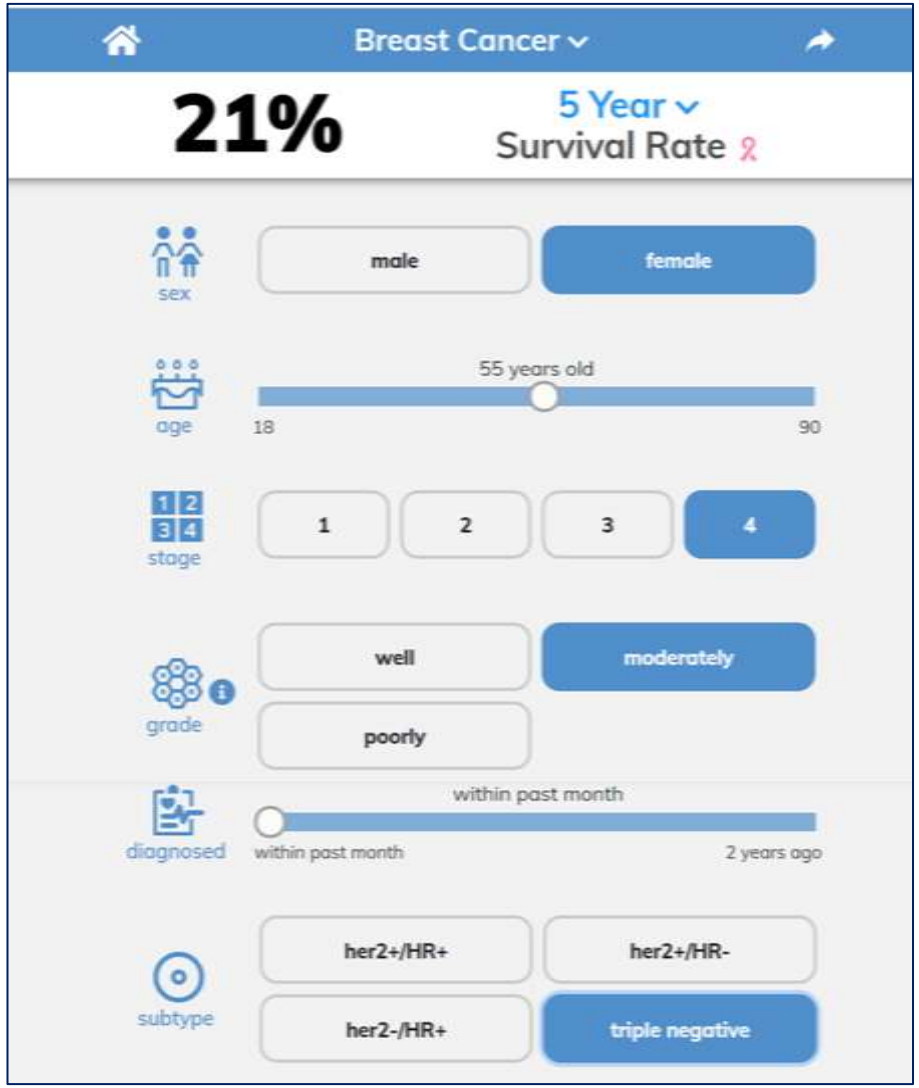
77% found the survival scenarios the same or better than expected

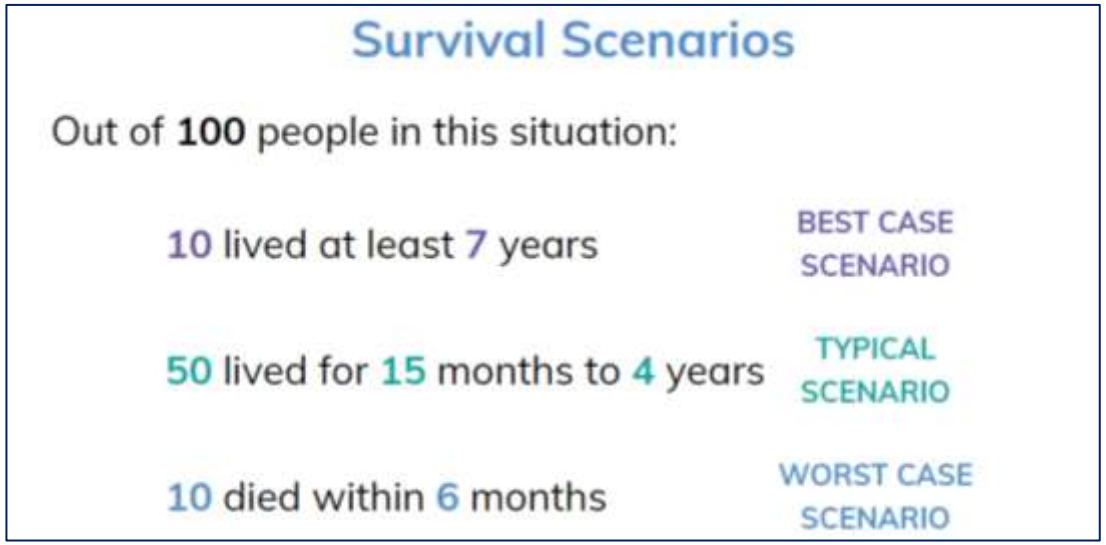
* agree and strongly agree (vs. unsure, disagree, strongly disagree)

Nahm, et al. Supportive Care in Cancer 2022

https://cancersurvivalrates.com

website for people affected by cancer and clinicians





Survival information for all types and stages of cancer

- More reliable information for people googling “how long have I got?”
- >3 million patients, cancer diagnoses from 2000 to 2016, followed until 2017
- Cox proportional-hazards models using NCI SEER data; 1, 2, 3, 5, 10 yr survival models

Conclusion

- Help patients understand the likely trajectory of metastatic breast cancer
- Conversations about prognosis, values, priorities and end of life wishes, are important and need to be part of routine care
- Absence of questions does not equate with unwillingness to know
- Key timepoints (disease progression or expected survival < 12 months) can serve as ‘triggers’ for doctors to start a conversation
- Acknowledge patients as individuals with unique information needs
  - type, timing and amount of prognostic information

THANK YOU FOR JOINING US!