Does life ever look the same again? Trajectories of functioning in cancer survivors and their partners/caregivers

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3rd Victorian Cancer Survivorship Conference 2020

Overview

- “Functioning” limited to psychological wellbeing
- What we know about survivors & partners/caregivers
  - Cancer Survival Study
  - Partners & Caregivers Wellbeing Study
- Some obvious gaps

Post-treatment ……

- For 1/3 survivors, post-treatment symptoms are equivalent to during treatment
  - ✓ Fatigue
  - ✓ Depression or mood disturbance
  - ✓ Sleep disturbance
  - ✓ Pain
  - ✓ Cognitive limitations
- QoL negatively associated with symptom burden

Deshields et al, Supportive Care in Cancer 2014; Wu et al, Cancer Nursing 2015

Longitudinal studies => Trajectories

NSW Prostate Cancer Care and Outcomes Study (PCOS) - 2500 men; QoL after **prostate cancer** [A/Prof David Smith, CCNSW)]

The ColoREctal Wellbeing (CREW) study - 1,000 **colorectal cancer patients**; life after their illness [Prof Claire Foster, Macmillan Survivorship Research Group]

45 and Up Study – more than a quarter of a million people (1/10 NSW **men and women aged over 45**) - healthy ageing [Prof Emily Banks, SAX Institute]

Australian population based longitudinal studies (NSW/VIC cancer registries)

Cancer Council New South Wales
Centre for Health Research & Psycho-oncology (CHeRP)

Cancer Survival Study
Partners & Caregivers Wellbeing Study

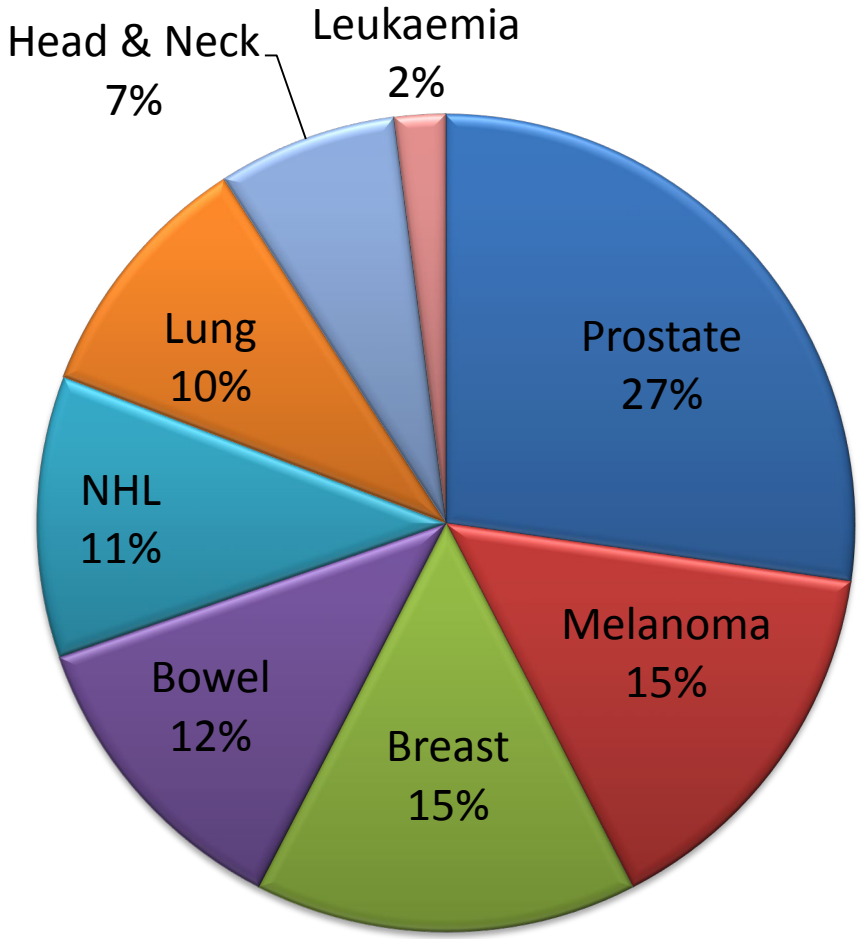
- Hospital Anxiety & Depression Scale
- Distress Thermometer
- Supportive Care Needs Survey – SF34
- EORTC Quality of Life Questionnaire Core 30

Project teams include:
Dr Allison Boyes,
A/Prof Sylvie Lambert
Alison Zucca, Alix Hall,
Christophe Lecathelinais
Prof Cate D'Este
Prof Afaf Girgis

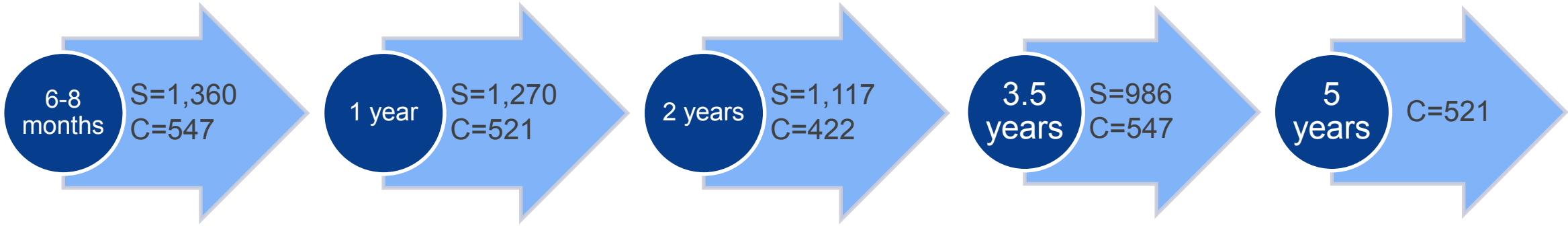
Funding: National Health & Medical Research Council, Cancer Council NSW, Honda Foundation, Hunter Medical Research Institute, University of Newcastle

Cancer Survival Study
Partners & Caregivers Wellbeing Study

Survivors' cancer diagnosis (n= 1,453)



Cancer Survival Study
Partners & Caregivers Wellbeing Study



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JOURNAL OF CLINICAL ONCOLOGY | ORIGINAL REPORT

Prevalence and Predictors of the Short-Term Trajectory of Anxiety and Depression in the First Year After a Cancer Diagnosis: A Population-Based Longitudinal Study

Allison W. Boyes, Afaf Girgis, Catherine A. D'Este, Alison C. Zucca, Christophe Lecathelinais, and Mariko L. Carey

Psycho-Oncology

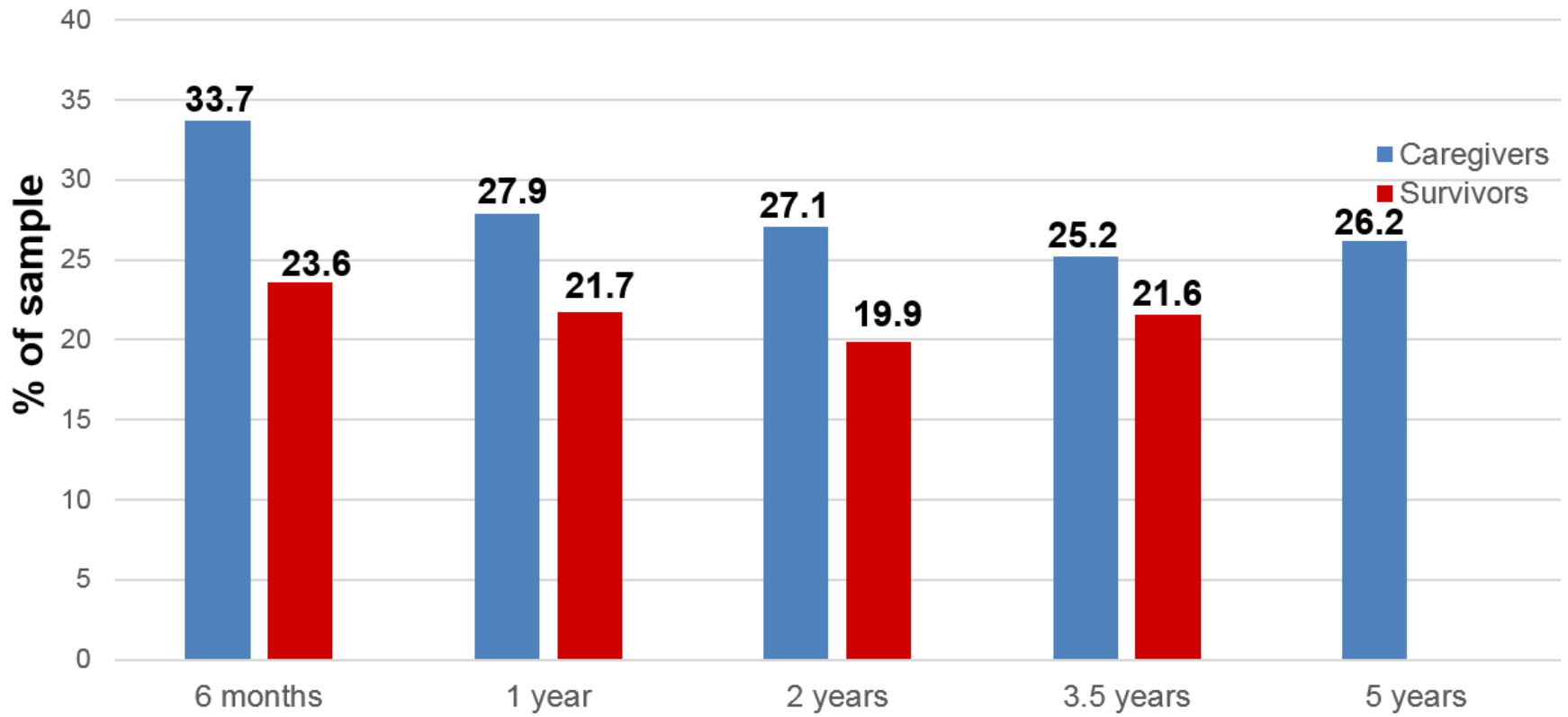
Psycho-Oncology (2012)

Published online in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.3166

Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs

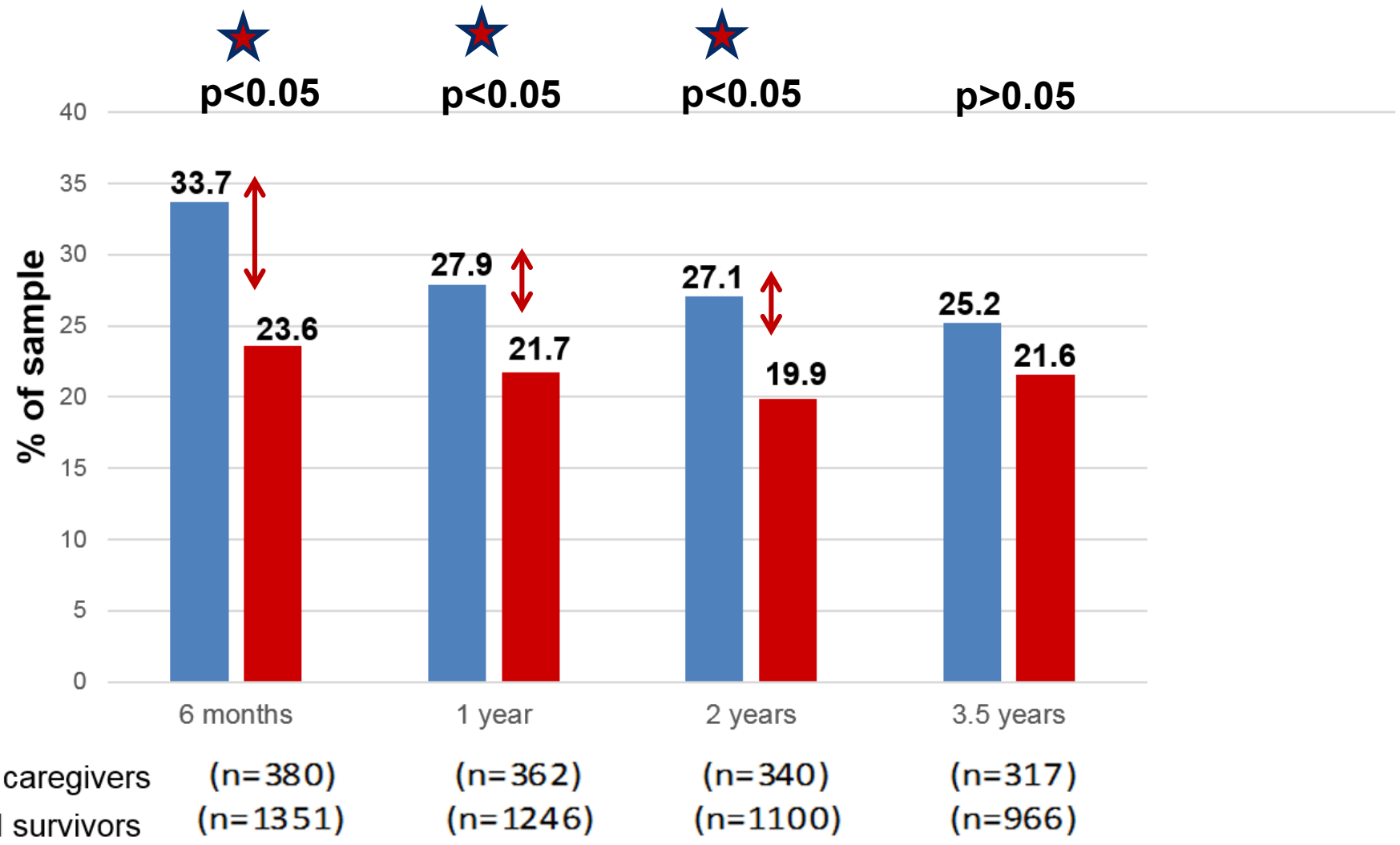
Afaf Girgis[1], Sylvie D. Lambert[1]*, Patrick McElduff[2], Billie Bonevski[2], Christophe Lecathelinais[3], Allison Boyes[2] and Fiona Stacey[2]

Anxiety (HADS ≥8): Survivors vs carers

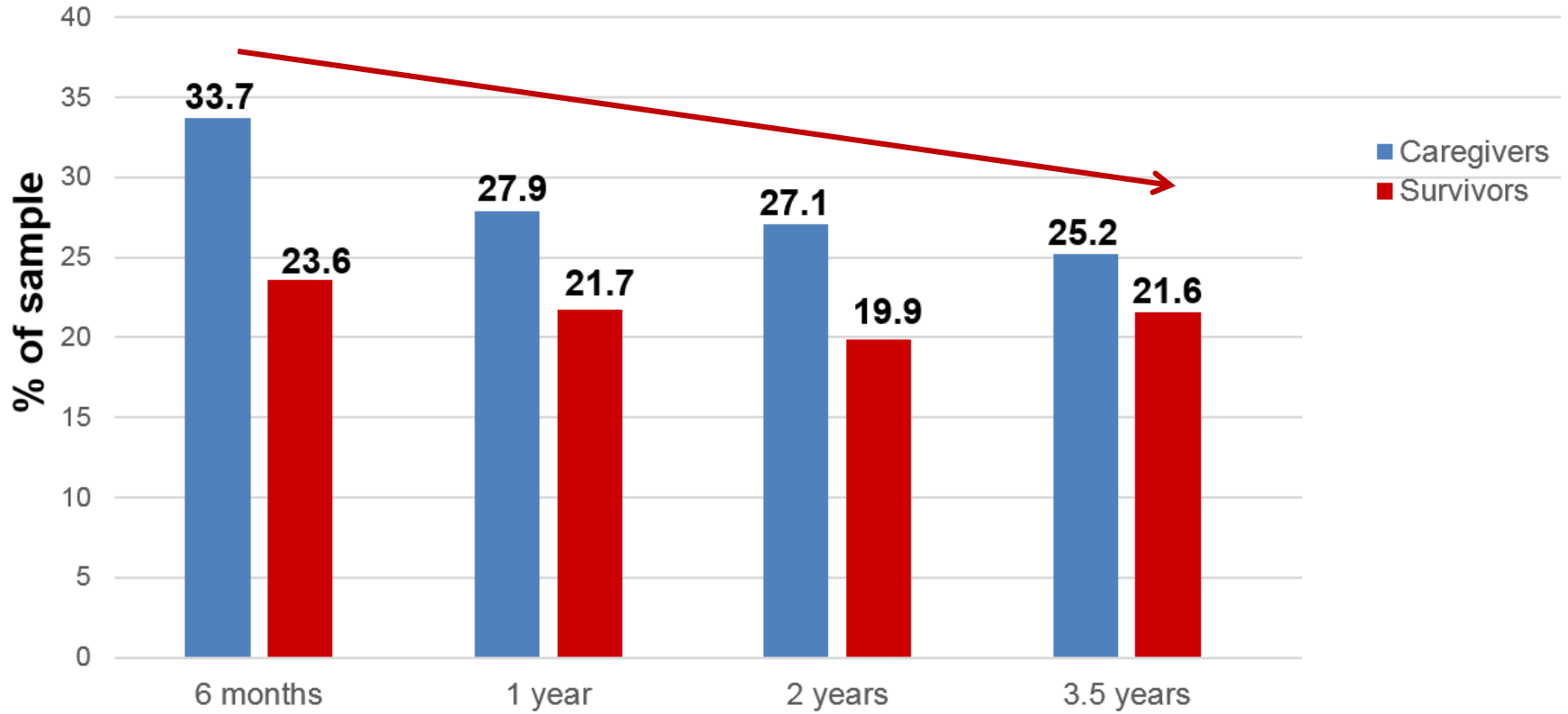


N caregivers	(n=380)	(n=362)	(n=340)	(n=317)	(n=282)
N survivors	(n=1351)	(n=1246)	(n=1100)	(n=966)	

Anxiety (HADS ≥8): Survivors vs carers

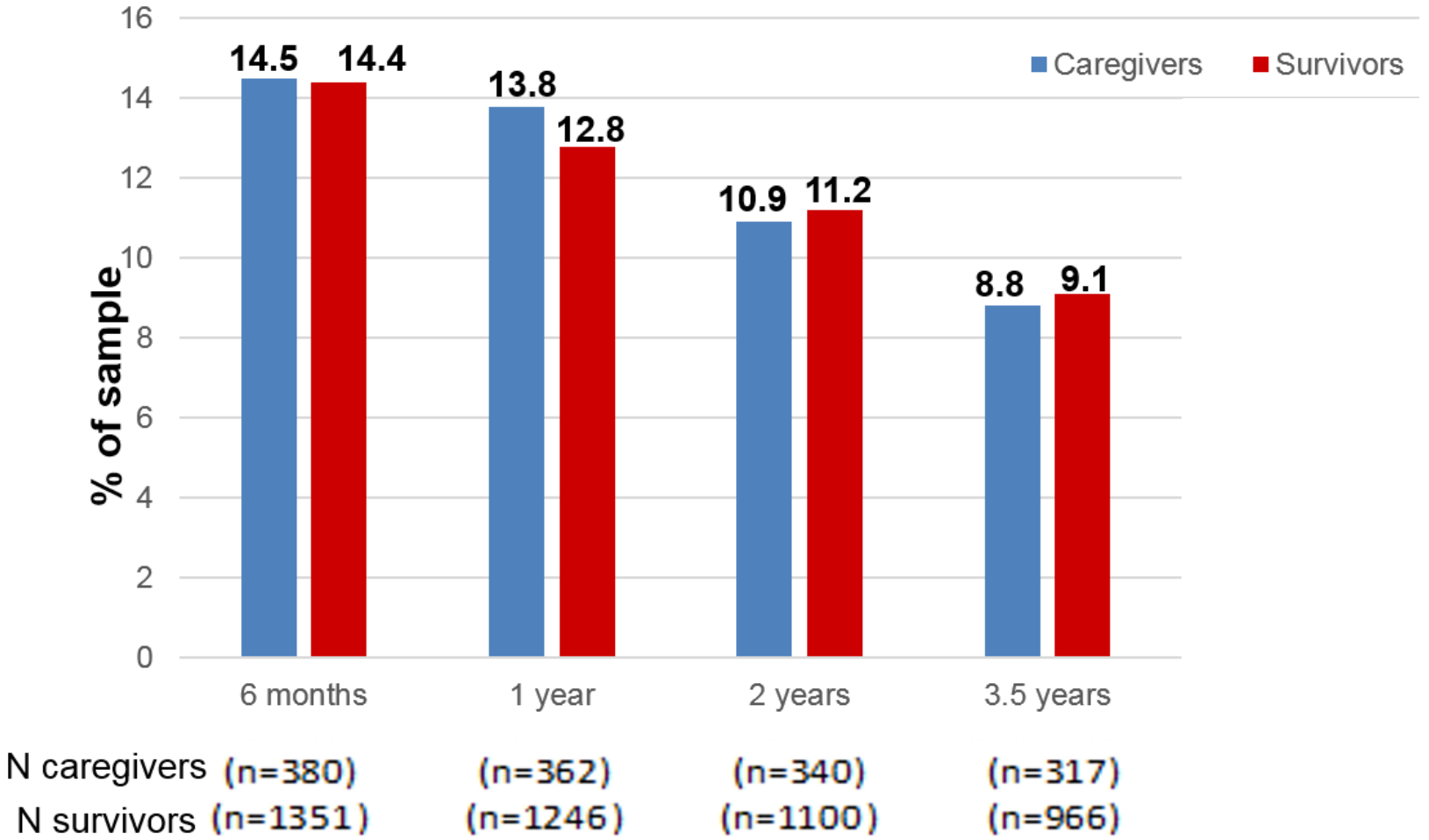


Anxiety (HADS ≥8): Carers over time



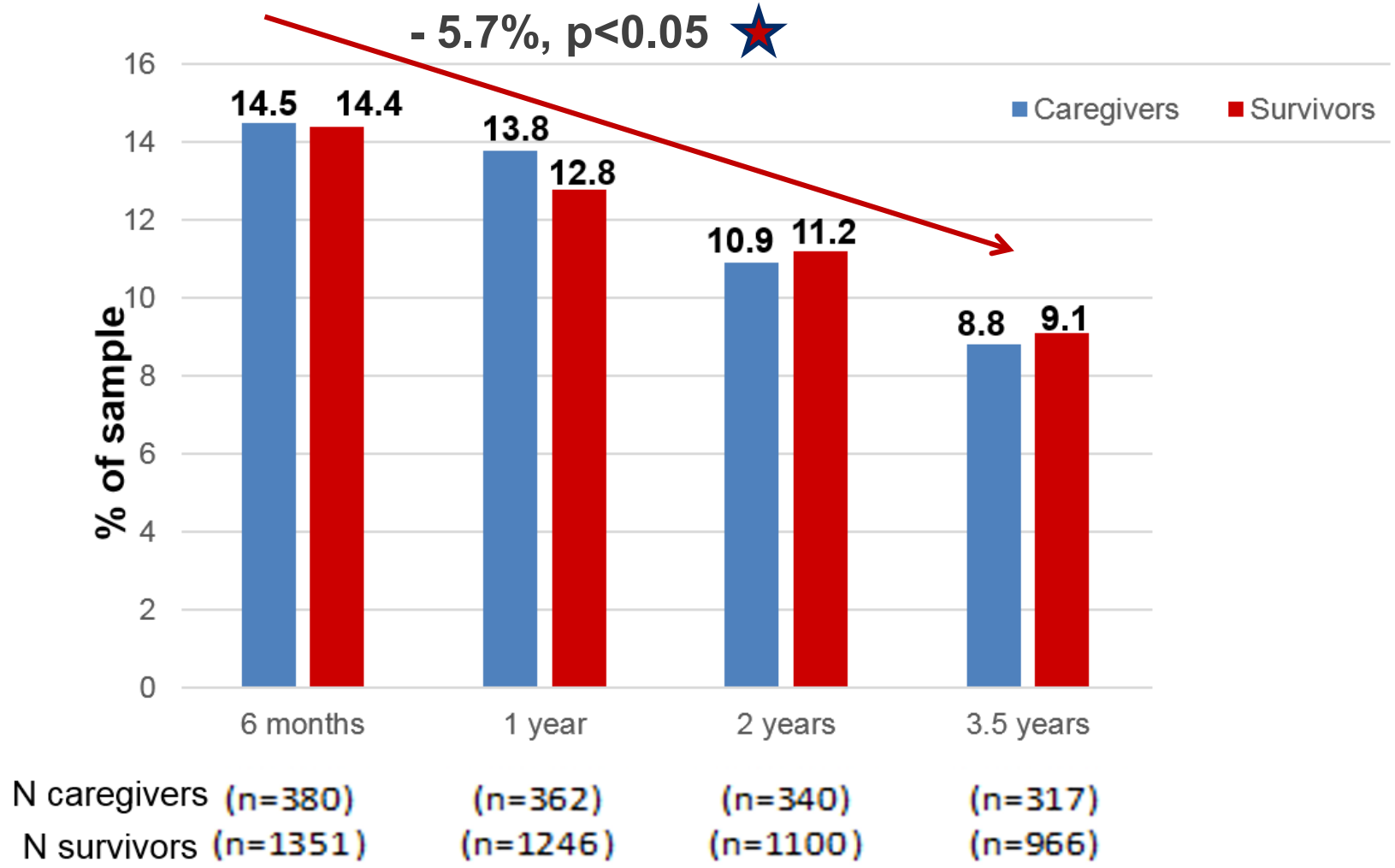
N caregivers	(n=380)	(n=362)	(n=340)	(n=317)
N survivors	(n=1351)	(n=1246)	(n=1100)	(n=966)

Depression (HADS ≥8): Survivors vs carers

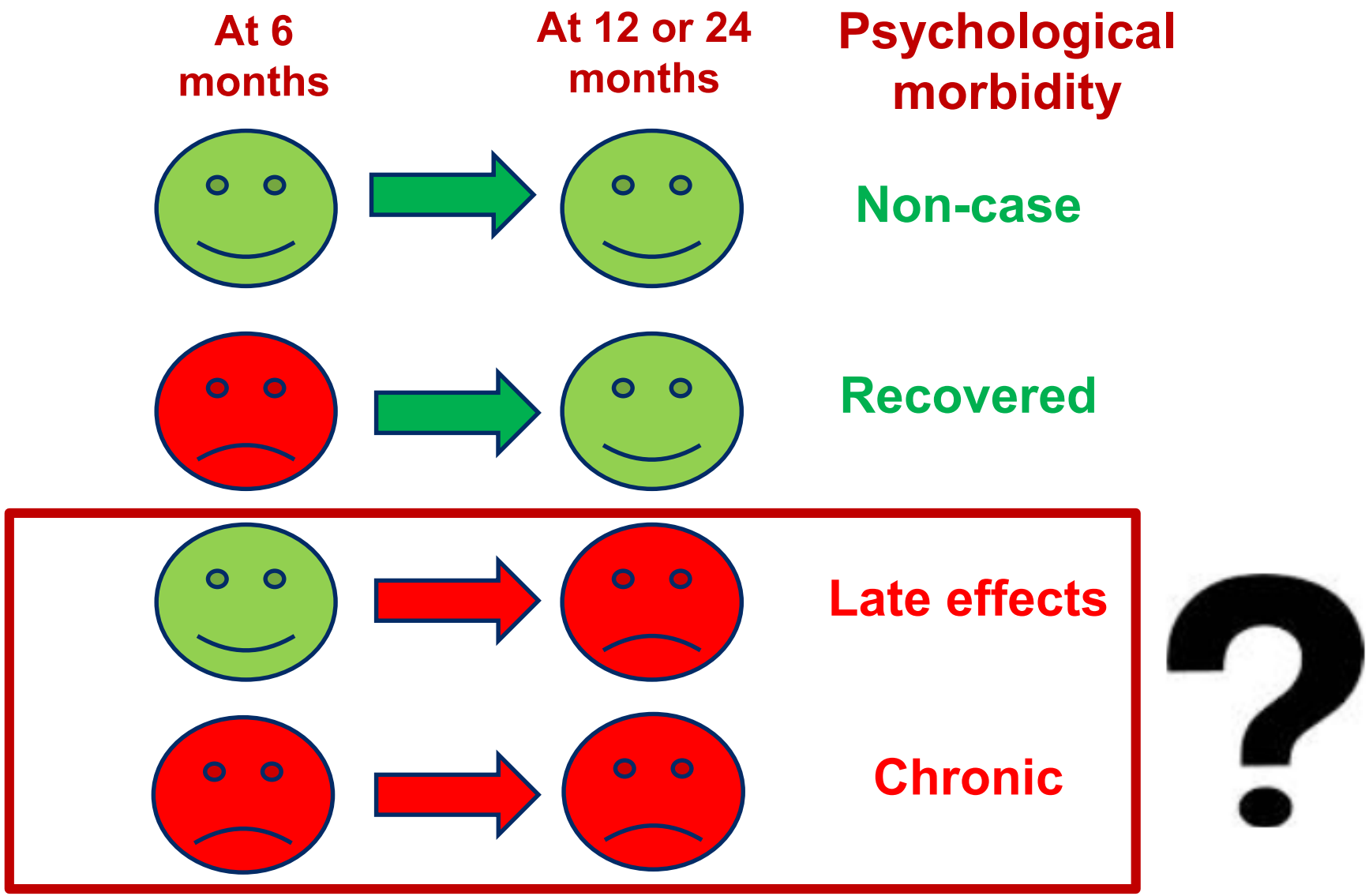


No significant differences b/w survivors and caregivers

Depression (HADS ≥8): Carers over time



Trajectories of psychological morbidity



Anxiety & depression 1 year post-diagnosis

Late/chronic effects (≥8):

- Anxiety in 21%
- Depression in 14%

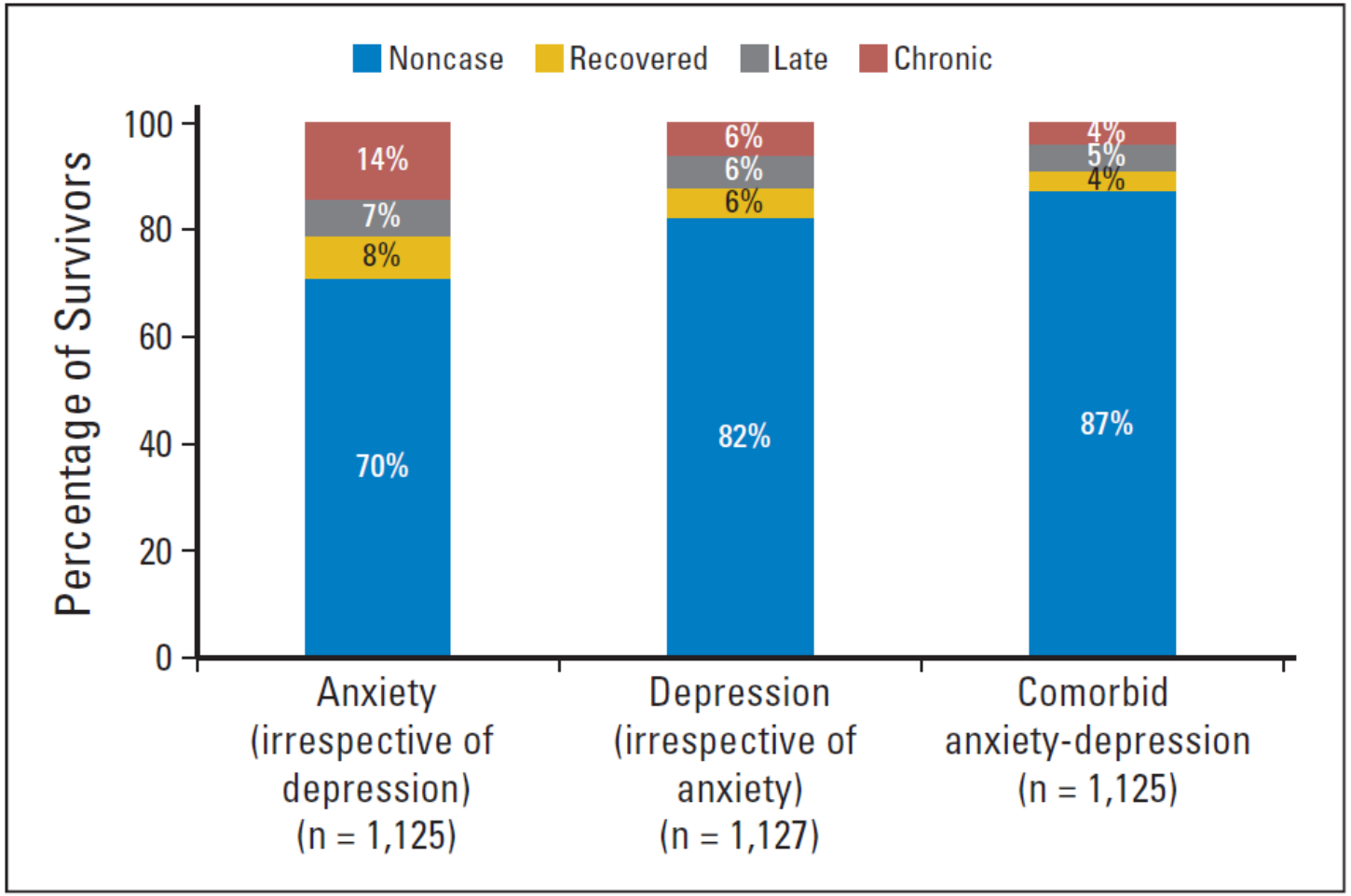


Fig 1. Prevalence of anxiety, depression, and comorbid anxiety-depression pathways in the first year after diagnosis.

Boyes, Girgis et al, JCO 2013

What we DO know …..

- Many survivors & caregivers adjust well - **considerable resilience** and adaptability
- BUT sizable group have **delayed/chronic** anxiety/depression
- **Predictors** of poorer outcomes: poor physical health, avoidant coping, low emotional and informational support, caregiver burden
- Caseness at T1 predicts future caseness => early intervention may avoid later/chronic problems

We also know …..

- Compared to Anglo-Australians (n=319), **immigrant** cancer survivors (n=277 Chinese, Arabic, Greek, 1-6 years post-Dx, 12 top tumour groups) have worse psychological and QoL outcomes
- 2018 - first published assessment of distress among **Indigenous Australian** cancer survivors - clinically significant distress in 35% (n=155, 6 months post-Dx); lower HRQoL than other Australians

European Journal of Cancer (2013) 49, 1948–1956

Inferior health-related quality of life and psychological well-being in immigrant cancer survivors: A population-based study

Phyllis N. Butow[a,*,h], Lynley Aldridge[a,h], Melanie L. Bell[a,h], Ming Sze[a,h], Maurice Eisenbruch[b,h], Michael Jefford[c,d,h], Penelope Schofield[c,d,h], Afaf Girgis[e,h], Madeleine King[a,h], Priya Duggal-Beri[a,h], Joshua McGrane[a,f,h], David Goldstein[g,h]

Supportive Care in Cancer (2018) 26:1737–1746
https://doi.org/10.1007/s00520-017-3995-y

ORIGINAL ARTICLE

Psychological distress among Indigenous Australian cancer survivors

Gail Garvey[1] · J. Cunningham[1] · M. Janda[2] · V. Yf He[1] · P. C. Valery[3]

Does life ever look the same again?
We need to know so much more …..

- Longitudinal studies of immigrants, Indigenous Australians, rural survivors
- Trajectories beyond 5 years, eg late effects of newer treatments
- How to screen for psychosocial wellbeing beyond end of treatment
- How to reach caregivers
- How to make interventions more accessible for all
- +++++
- +++++
- +++++

Thank you

"Two years after diagnosis it is hard getting used to the new me.

I don't have the strength, flexibility or stamina that I used to, and have to adjust to achieving less each day than my mind expects me to…

Still, I am generally not in pain and happy to still be here with my family and friends.

I have down-sized my career which has had a financial impact, but I think has achieved a better work/life balance for this stage in my recovery."

(Male leukaemia survivor, 39 years old, 2 years post-diagnosis)

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