

# The financial burden of cancer – the unspoken side effect.

Prof Bogda Koczwara AM  
February 3<sup>rd</sup>, 2017

# Poverty is an unrecognised late effect of cancer

**with disproportional impact on those already disadvantaged**

**SPECIAL REPORT** Doctors attack rich-poor divide in new-generation medicine

# Cancer drug shame

**PAUL HEINRICHS**

ACCESS to new-generation, life-prolonging cancer drugs has shamefully been allowed to develop into a two-tier system — one for the rich, another for everyone else.

Two of Victoria's leading cancer specialists have attacked federal health authorities for doing nothing to ensure that the drugs — which can cost up to \$60,000 — are available to everyone, not just the wealthy.

The clinical director of Peter MacCallum Cancer Centre, John Zalcborg, said the Federal Government's Pharmaceutical Bene-

pharmaceuticals is under siege from economic, ethical and equity issues.

Known as "biologicals" because they use the body's own systems to defeat or slow cancers, the new generation of drugs can cost tens of thousands of dollars a year, placing enormous financial pressure on people suffering potentially fatal illnesses.

The situation is so bad that a third of Victorian cancer specialists said they would not tell patients about the drugs if they thought they could not afford them, because it would "worry the patient" and the doctor would "feel bad"

treatment? Rationing, in this sense, is the deliberate withholding of a treatment which will be beneficial because of an economic imperative."

The emotional impact of the situation on doctors and patients was revealed by a recent survey conducted by clinicians and researchers at Peter MacCallum. It was sent to 274 Victorian oncologists and 78 per cent responded.

The survey posed questions on hypothetical scenarios that reflected real cases of positive improvements following the use of high-cost new drugs that were not subsidised.

Depending on the scenario



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ORIGINAL ARTICLE

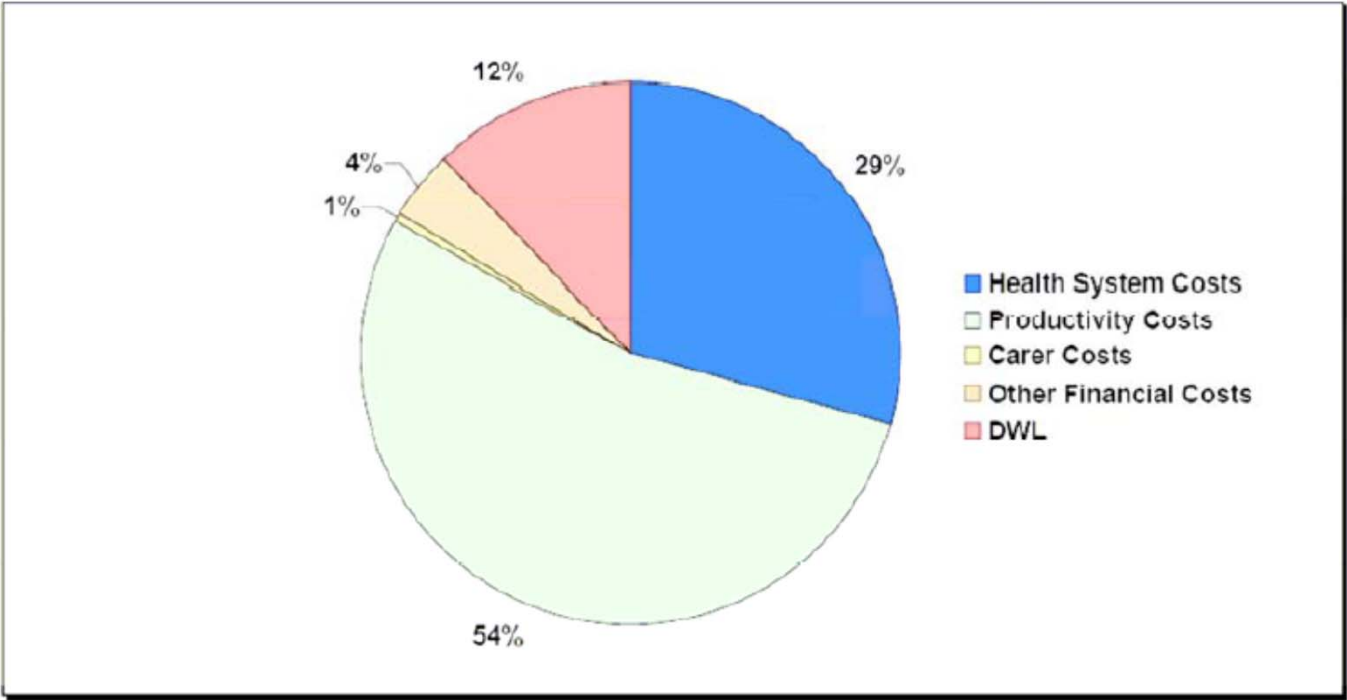
## Cost of cancer care for patients undergoing chemotherapy: The Elements of Cancer Care study

Robyn L WARD,<sup>1</sup> Maarit A LAAKSONEN,<sup>1</sup> Kees VAN GOOL,<sup>2</sup>  
Sallie-Anne PEARSON,<sup>1\*</sup> Ben DANIELS,<sup>1</sup> Patricia BASTICK,<sup>1</sup> Richard NORMAN,<sup>2</sup>  
Changhao HOU,<sup>2</sup> Philip HAYWOOD<sup>2</sup> and Marion HAAS<sup>2</sup>

**Table 2** Mean (10%–90% quantiles) monthly (28 day) costs (in 2011 Australian dollars) of cancer care by funding agent, presented according to site and stage of cancer

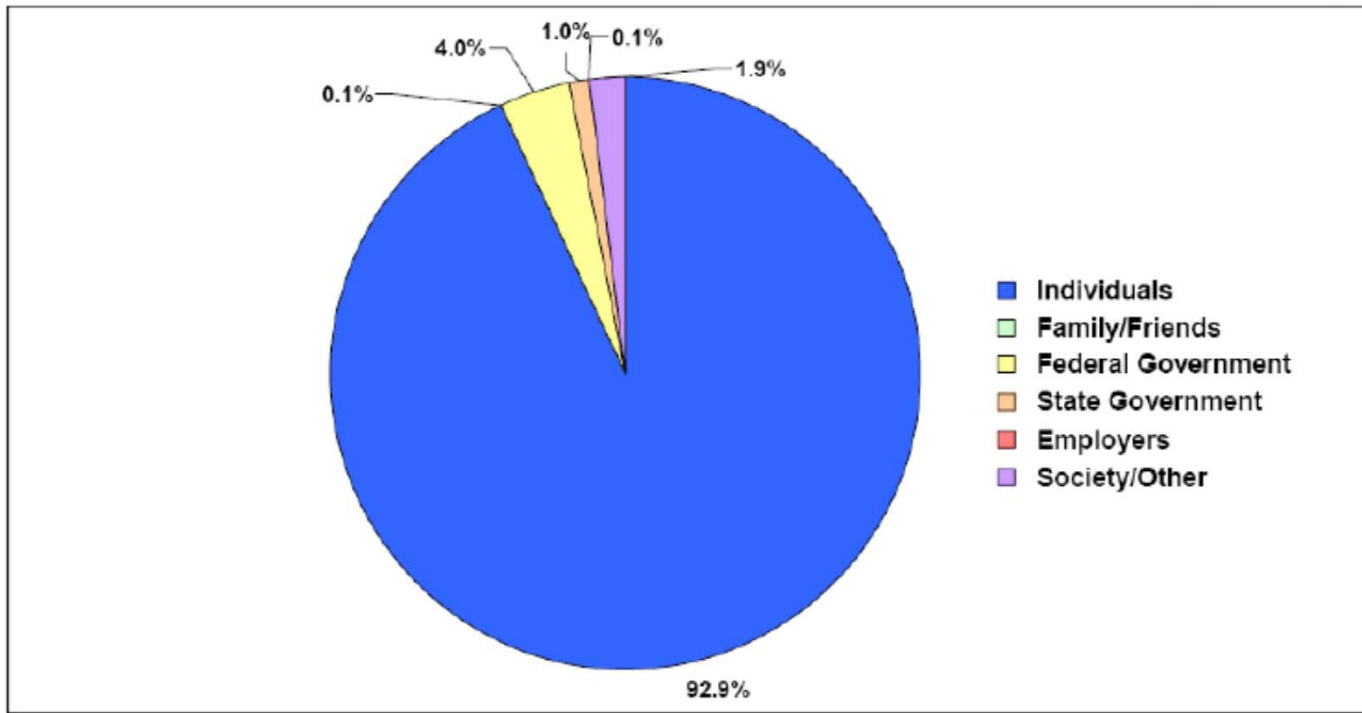
Cancer site and stage	N	Total	Commonwealth government <sup>†</sup>	State government <sup>‡</sup>	Private health insurers <sup>§</sup>	Patient out-of-pocket <sup>¶</sup> (%)				
Overall	476	4162 (1018–8098)	2242 (488–4386)	54%	607 (0–1782)	14%	1075 (0–3182)	26%	238 (24–545)	6%
Breast adjuvant	149	3604 (714–7660)	2639 (563–5984)	73%	225 (0–416)	6%	541 (0–1350)	15%	199 (26–422)	6%
Breast metastatic	108	4046 (1279–7633)	1939 (557–3544)	48%	647 (0–2059)	16%	1219 (0–3426)	30%	240 (21–565)	6%
Colorectal adjuvant	54	2853 (735–8098)	1228 (374–2408)	43%	322 (0–548)	11%	1032 (0–3694)	36%	271 (33–622)	10%
Colorectal metastatic	102	5191 (1846–8928)	2393 (548–4626)	46%	718 (0–2193)	14%	1770 (0–3881)	34%	311 (27–738)	6%
NSCLC adjuvant	13	3251 (492–7379)	1429 (321–2881)	44%	493 (0–1123)	15%	1144 (0–5100)	35%	186 (17–602)	6%
NSCLC metastatic	50	5622 (2210–9338)	2710 (733–4065)	48%	1770 (0–5531)	32%	969 (0–2947)	17%	172 (18–465)	3%

LIFETIME FINANCIAL COST OF CANCER, NSW, 2005, BY TYPE OF COST (% TOTAL)



Cost of cancer in NSW. TCCNSW 2008

### LIFETIME ECONOMIC COST OF CANCER, NSW, 2005, BY WHO BEARS THE COST (% TOTAL)



Cost of cancer in NSW. TCCNSW 2008



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COST – FACIT (Version 1)

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	Not at all	A little bit	Some- what	Quite a bit	Very much
FT1 I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.....	0	1	2	3	4
FT2 My out-of-pocket medical expenses are more than I thought they would be.....	0	1	2	3	4
FT3 I worry about the financial problems I will have in the future as a result of my illness or treatment.....	0	1	2	3	4
FT4 I feel I have no choice about the amount of money I spend on care.....	0	1	2	3	4
FT5 I am frustrated that I cannot work or contribute as much as I usually do.....	0	1	2	3	4
FT6 I am satisfied with my current financial situation.....	0	1	2	3	4
FT7 I am able to meet my monthly expenses.....	0	1	2	3	4
FT8 I feel financially stressed.....	0	1	2	3	4
FT9 I am concerned about keeping my job and income, including work at home.....	0	1	2	3	4
FT10 My cancer or treatment has reduced my satisfaction with my present financial situation.....	0	1	2	3	4
FT11 I feel in control of my financial situation.....	0	1	2	3	4

# Prevalence of financial burden

- 47% patients with cancer reported significant/catastrophic financial hardship (Chino 2014)
- Survivors median 7.3 yrs after diagnosis - 48% report difficulties financially (Zafar 2015)
- 86-90% of pts with advanced cancer report financial distress (Delgado-Guay 2015)
- Patients with cancer 2.5 x more likely to go bankrupt than controls (Ramsey 2013)



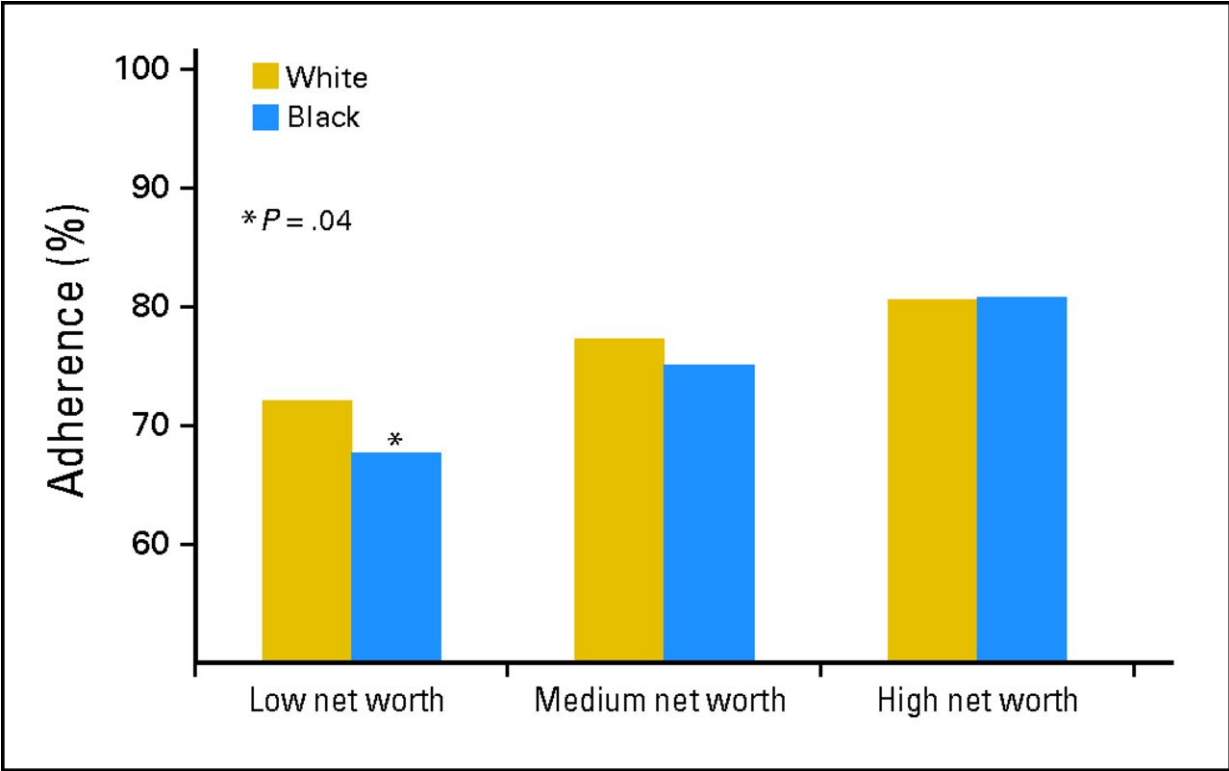
# Impact

- High financial burden was associated with **poorer quality of life** even when adjusting for income, employment, comorbidities or disease status (Zafar)
- In cohort of pts with advanced cancer, 30% rated **financial distress as more severe than physical, family and emotional distress – correlated with anxiety, depression and poor QOL** (Delgado-Guay 2015)
- Bankruptcy associated with **higher mortality** - HR 1.79 (Bansal ASCO 2015)

# What do patients do to cope?

- Lifestyle alteration 89%
  - Spending less on leisure
  - Spending less on food and clothing
  - Borrowing money
  - Spending savings
- Care alteration 39%
  - Not filling prescription or taking less drugs

Racial difference in adherence to hormonal therapy within each net worth category.



Dawn L. Hershman et al. JCO doi:10.1200/JCO.2014.58.3062

# Not just a US problem!

Patient  
DOI 10.1007/s40271-016-0204-x



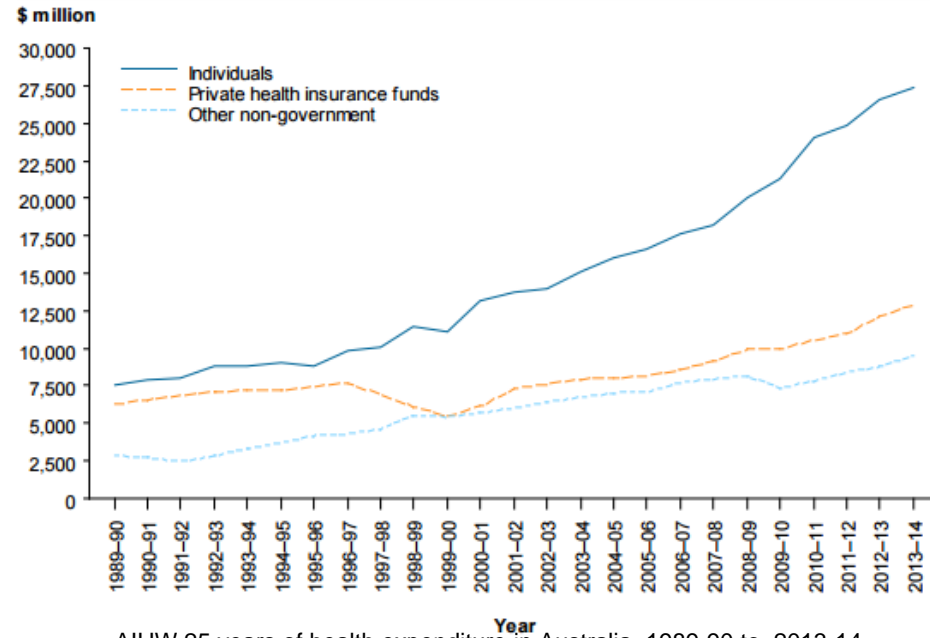
SYSTEMATIC REVIEW

## A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay

Louisa G. Gordon<sup>1</sup> · Katharina M. D. Merollini<sup>2</sup> · Anthony Lowe<sup>3,4</sup> · Raymond J. Chan<sup>5,6</sup>

- 25 studies included (last 3 years)
- Over 270,000 cancer survivors
- All cancer types
- USA (14), Singapore (1), Korea (1), Ireland (2), Italy (1), Canada (2), Australia (1), India (1), ASEAN (2)
- Most cross sectional (72%)

Non-gov funding of health expenditure



AIHW 25 years of health expenditure in Australia, 1989-90 to 2013-14

## Financial toxicity in clinical care today: a “menu without prices”<sup>1</sup>

Out-of-pocket costs are rising rapidly and can influence treatment decisions and health outcomes

Australia delivers health outcomes that rank well internationally, with per capita spending demonstrably less than that of the United States. Of concern, Australia’s out-of-pocket costs for health care are sixth highest among Organisation for Economic Cooperation and Development countries,<sup>2</sup> despite universal health insurance. These out-of-pocket expenses accounted for 57% of non-government health expenditure in 2011–12, or over 17% of all health care expenditure.<sup>3</sup> Health care costs in Australia continue to rise well above the consumer price index. The net burden of costs are reported by clinicians to influence some decisions that patients make, with the potential for detrimental health outcomes for individuals and for Australia’s health as a whole.

The average equivalised weekly disposable household income in 2013–14 was \$998, with a median of \$844.<sup>4</sup> About half of all households therefore have a weekly net

demonstrate that public surgical waiting times for a sample of cancers are very short.<sup>5</sup> Publicly available data on waiting times and service quality are critical for supporting informed treatment decisions, especially when out-of-pocket expenses can vary from zero to tens of thousands of dollars for the same procedure.

Value in health care is defined as outcomes relative to cost.<sup>6</sup> In considering this from a patient’s perspective, it is imperative to not only question outcomes but to understand the true cost for the whole episode of care — the out-of-pocket expenses, the contribution made by the community through Medicare, and any supplementary private insurance. Informed choice should be based on more than the costs charged by an individual practitioner and those incurred by related pathology, imaging and anaesthetics. Informed choice now needs also to account for the extreme variations in the prices charged by

*MJA June 2016*

# Cancer and employment:

- Cancer survivors are **more likely to be unemployed** than healthy controls (RR 1.37)
- Up to **30% of previously employed cancer survivors do not return to work** as late as 5 years after diagnosis
- Cancer patients have **higher risk of early retirement** (RR 1.6)
- Failure to return to work in cancer survivors is associated with **reductions in quality of life and poorer financial status**

“Sometimes I had a sleep at lunchtime. That helped if I was really tired. I just used to put the phone on the alarm, and go in the car and fall asleep, then go back and start again”

Breast ca survivor, 48 y. Knott et al 2014

# Return to work after cancer rehabilitation

Mehnert et al

**Table 2.** Time period of return to work (RTW) and reemployment after rehabilitation (N=568).

Employed patients	N (t <sub>0</sub> )	Time period to RTW / re-employment				P-value	φ / η <sup>2</sup>
		Patients who returned to work immediately after rehabilitation		Weeks until RTW / re-employment			
		N	%	Mean	SD		
Baseline employment status						<0.001 <sup>a</sup> / <0.001 <sup>b</sup>	0.68 <sup>a</sup> / 0.24 <sup>b</sup>
Patients working	268	228	85.1	1.64	2.46		
Patients on sick leave	290	48	16.6	8.90	9.83		
Unemployed patients	10	2	20.0	21.60	16.67		
Total	568	278	48.9	5.68	8.60		
Social class						0.008 <sup>a</sup> / 0.63 <sup>b</sup>	0.13 <sup>a</sup>
Lower social class	133	53	39.8	6.23	8.23		
Middle social class	343	169	49.3	5.41	8.44		
Upper social class	92	56	60.9	5.89	9.64		
Cancer entity						0.001 <sup>a</sup> / <0.001 <sup>b</sup>	0.20 <sup>a</sup> / 0.05 <sup>b</sup>
Breast cancer	348	171	49.1	5.19	7.98		
Gynecological cancers	81	38	46.9	5.23	6.77		
Head and neck cancers	39	14	35.9	8.03	10.31		
Skin cancer	38	30	78.9	2.76	6.00		
Colon/rectum cancer	36	16	44.4	10.21	13.41		
Lung cancer	10	1	10.0	13.70	14.21		
Hematological neoplasias	16	8	50.0	5.13	7.53		

<sup>a</sup> Significance and effect size refer to group differences in patients who returned to work immediately after rehabilitation.

<sup>b</sup> Significance and effect size refer to group differences in weeks until RTW/reemployment.



# The most vulnerable

- very young, very old
- low income
- Manual labour/low education
- multiple chronic conditions
- geographical isolation
- CALD/ATSI\*

# Unemployment and financial toxicity

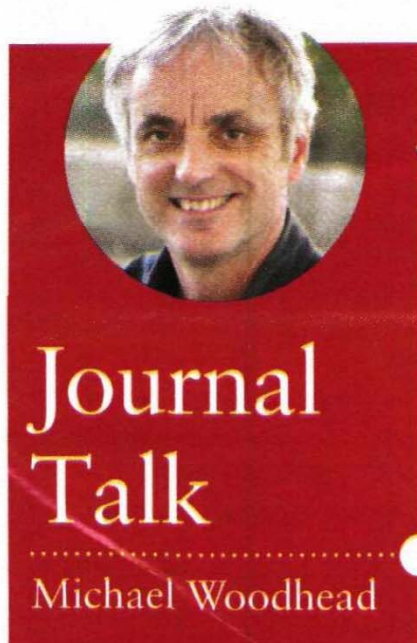
- Cross sectional survey 2 hospitals oncology outpatients – metro and rural
- 255 responses
- 67% change of employment, 63% reduced household income
- Unemployment – a major driver of financial impact of cancer

*Paul C et al Supp Care Cancer 2016*

# Work after cancer - impact

- Financial
- Social
- Self esteem
- Distraction from symptoms
- ? survival

# How we dodged the GFC — and cancer



unemployment link was no longer evident.

This suggested that healthcare systems such as Australia's Medicare have a protective effect against the adverse health impact of unemployment, they concluded.

"Our study makes a strong case for universal health coverage and its possible moderating effect on unemployed populations during economic downturns," they wrote.

Specifically, they pointed to people on low incomes having access to cancer screening, chemotherapy, radiotherapy and surgery as being factors that would explain the protective effect of a universal healthcare system against cancer deaths.

# Economic downturns, universal health coverage, and cancer mortality in high-income and middle-income countries, 1990–2010: a longitudinal analysis

Mahiben Maruthappu\*, Johnathan Watkins\*, Aisyah Mohd Noor, Callum Williams, Raghil Ali, Richard Sullivan, Thomas Zeltner, Rifat Atun

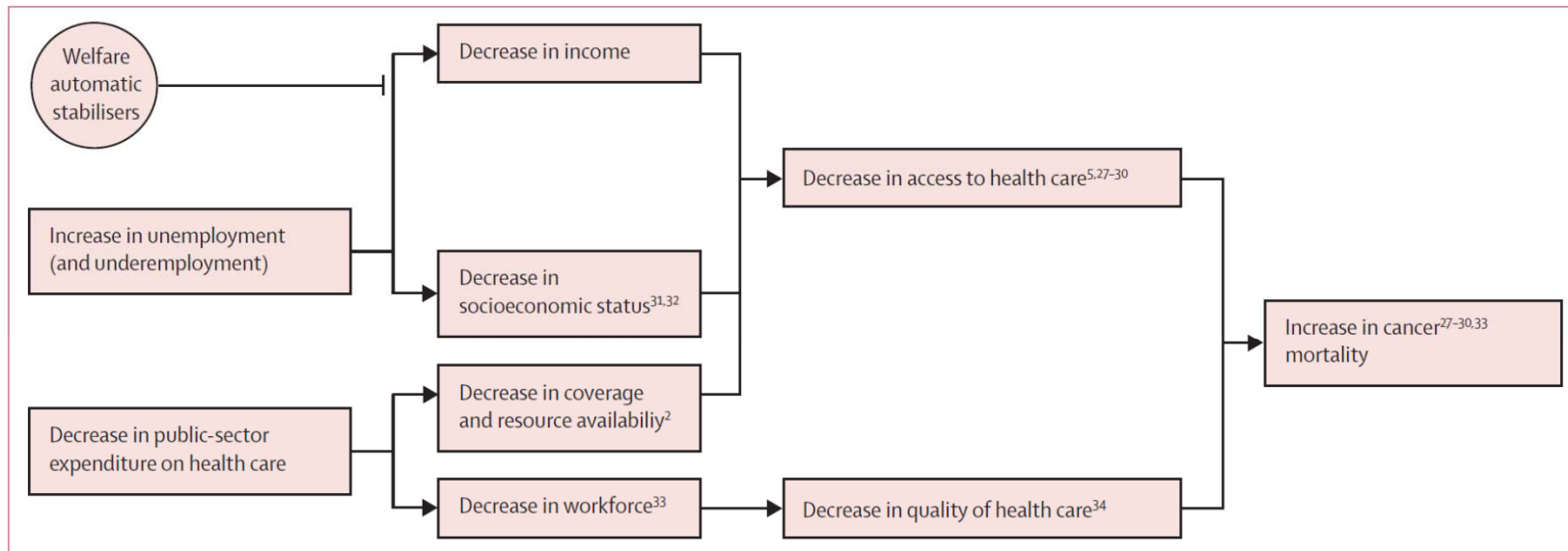
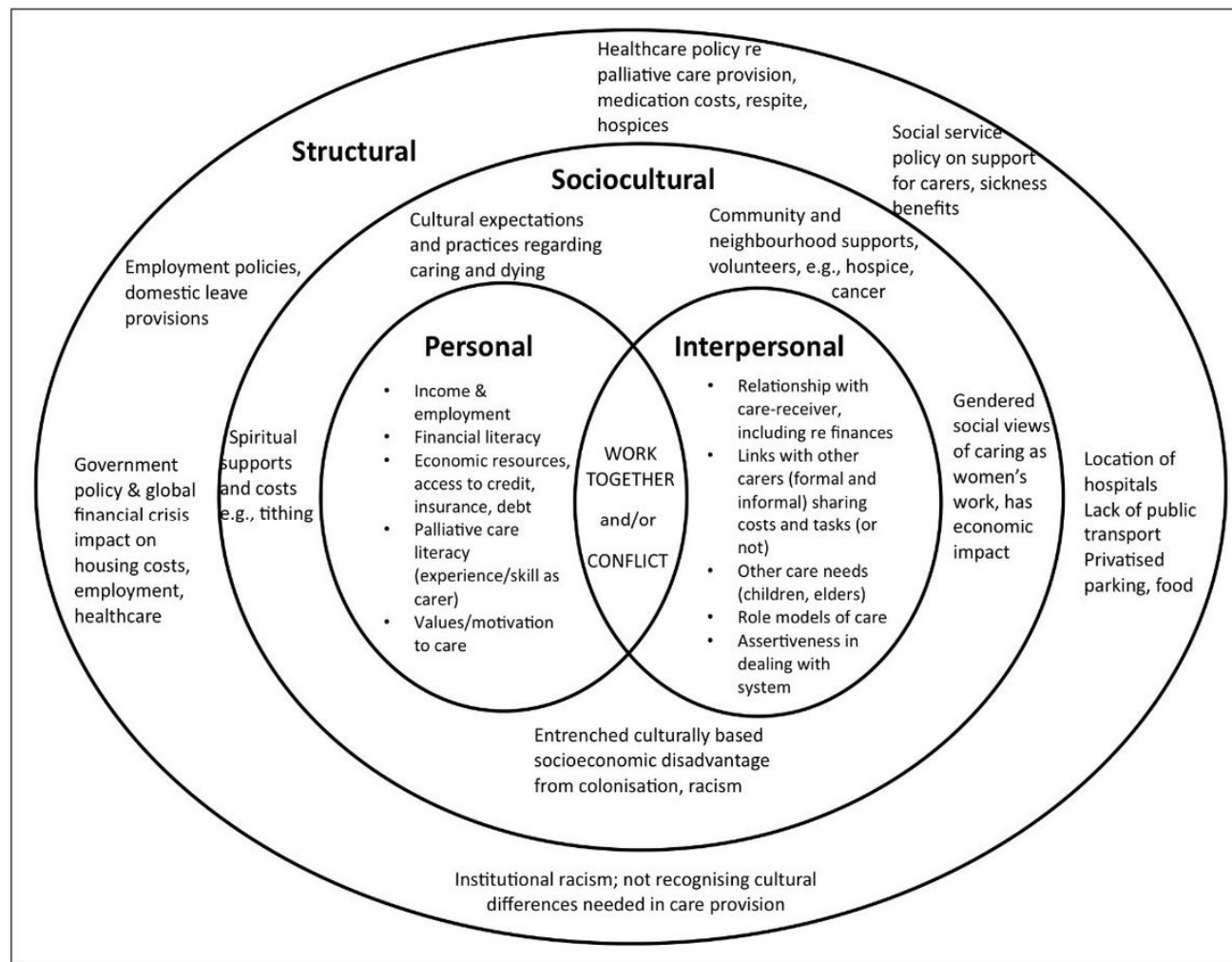


Figure 5: Possible causal pathways for the observed associations  
The flat arrowhead denotes a mitigating effect on the causal pathway.

# Whose problem is it?

- 54% oncologists reported being aware of pts financial circumstances and 43% discussed costs but... (Shrag 2007)
- 19% of patients recalled discussions though 52% had desire to do so (Bestvina 2014)



**Figure 1.** Four dimensions influence financial costs of care.

# Taking a broader view

- Financial literacy
  - individual, interpersonal, organisational
- Engage appropriate stakeholders – employers, payers, insurance agencies - in practice and research
- Invest in rehabilitation, including occupational rehab
- Invest in quality research
- Measure cost and value



**“Price is what you pay,  
value is what you get”**

*Warren Buffett*



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